Understanding Situational Meaning and Psychosocial Adjustment to Cancer: The Development of the Core Cancer Meanings Measure

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Summary

Introduction

It is well recognised that physical illness is associated with an increased risk of experiencing psychological problems and disorder and that there is considerable variation in the nature and severity of psychological reaction. This variance is not explained by physical disease characteristics alone. The meaning that is ascribed by patients to physical illness experiences has been examined as a potential explanatory variable. However the term 'meaning' has been used inconsistently and has been subject to semantic confusion within the literature. The term has been used to refer to discrete interpretations, the process of making sense of the occurrence of traumatic personal events and the outcome of this process of 'search for meaning'.

Meaning can also be distinguished in term of whether it is focused on cross-situational and global themes (e.g. 'The world is unjust, cruel and unfair') from a focus on interactions between an individual and situation specific events, so called situational meaning (e.g. 'I blame myself for having cancer'). Cancer is known to be associated with a number of specific psychological challenges many of which have informed research in psychosocial oncology. Global and situational meaning have been examined across a range of clinical populations. The existence of a range of valid and reliable assessment measures of global meaning has contributed to this literature. Although studies are beginning to examine global meaning in cancer, further development in understanding situational meaning in cancer has been hampered by the lack of any validated measure for this purpose.

Method

The Core Cancer Meanings Measure (CCMM) was developed through the application of a series of iterative stages consisting of item creation, revision, deletion and retention. Initially a sample of adult patients with a range of cancers was interviewed and transcripts were examined in order to develop a pool of items to form the first draft of the CCMM. This was circulated to an expert group of clinicians for comment and then administered to a further sample of patients to gather data to refine the scale. A final version of the CCMM was administered to people with breast, lung or colorectal cancer in order to gather data for analysis of psychometric performance.

Results

Fifty-three items were derived for the item pool from the content of interviews with 56 adult cancer patients. Following review by experts (n=9) 5 items were removed, an additional 7 items were added and 4 were rephrased. The resulting 55 item version was administered to a sample (n=17) of patients during a field test and 16 items were removed and 11 were rephrased. Following the addition of one item to reflect a theme that had not been covered the CCMM had 40 items. This was administered to a third patient sample (n=141) and data from these responses were analysed according to accepted psychometric criteria. Five items were removed on the basis of having high inter item correlations and a further 15 items were removed because of unacceptably low item-total correlations. A sub sample of this larger sample (n=29) completed the CCMM (40 item version) within three weeks of the first administration. Another 6 items were removed on the basis

of unacceptably low weighted kappa scores, leaving 14 items for principal components analysis (PCA). PCA with varimax rotation resulted in a three-component solution that accounted for 56% of variance. Most items that loaded highly on one component did not on the other two components. Items with high loadings were examined and the components were labelled 'Negative Meaning', 'Search for Meaning' and 'Positive Meaning'.

Conclusions

The CCMM has been developed as a short and clinically useful way of assessing the level of agreement with common situational meanings regarding cancer experience. These studies have demonstrated that the CCMM has excellent face and content validity, that it has good internal consistency and consists of three important dimensions that capture the essential elements of negative meaning, searching for meaning and positive meanings associated with cancer. The CCMM requires further validation and has considerable potential to extend current conceptual understanding of meaning in relation to adjustment to cancer. It is also likely that the CCMM could provide clinicians with an efficient way of assessing cognitions that are part of situational meaning in relation to cancer.

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White, C.A. and Espie C.A. (2003) Development of the Core Cancer Meanings Measure - Preliminary Data. *Abstracts of the European Congress of Behavioural and Cognitive Therapies*, Prague, September 2003

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SECTION ONE INTRODUCTION

Chapter 1 Adjustment to Illness and the Relevance of Meaning as a Heuristic Concept

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1.1 Overview

This chapter will outline the psychological impact of physical illness, focusing specifically on the impact that is known to be associated with cancer and cancer treatments. The attempts that have been made to understand contributory factors to variability in psychological morbidity will then be outlined, first examining a range of general psychological factors that are known to influence emotional reactions to illness and then focusing on cognitive variables that have been examined. This information is then considered with reference to work on adjustment and meaning from a philosophical and religious standpoint. This will lead then to a focus on the role of meaning in understanding adjustment to physical illness, examining this in general terms and outlining the ways in which this has been understood within health psychology research. These themes will be developed in the following chapter where there is extended coverage of conceptualisations of meaning within a cognitive perspective and a specific focus on cancer related psychosocial factors.

The literature is not comprehensively reviewed within this chapter but is cited for the purpose of providing the contextual background within which meaning and the measurement of meaning will then be outlined in Chapters 2 and 3. The prevalence of common psychological problems among the physically ill is described and provides an overview against which the specific psychological problems in cancer are then outlined. The fact that this thesis will be focused on cancer is the rationale for outlining further specific detail about psychological therapies in cancer. General material relating to work on understanding psychological adjustment to illness was selected and the

specific application of meaning to this process of understanding adjustment was outlined. Literature that has focused on other physical health problems and/or specific work to understand the way in which other psychological constructs contribute to adjustment was excluded because of the intention to ensure that this introductory chapter outlines general context and becomes more focused on the specific elements of meaning that will then be outlined.

1.2 Psychological Adjustment to Physical Illness

1.2.1 Changing Patterns of Physical Illness

Life expectancy was much lower at the beginning of the 20th century than it is now. Diseases such as tuberculosis and influenza were more common and among the conditions responsible for lowered life expectancy and high mortality rates. Although there are still a number of conditions that are associated with mortality, the nature and pattern of illness is such that advances in science and medicine have resulted in many more people living with chronic conditions such as heart disease, diabetes or hypertension. Many conditions that were fatal or life threatening can now be cured, treated or more effectively managed. The net effect of these changing epidemiological patterns and scientific advances is that many more now face the psychosocial challenges and impacts of living with a physical illness than was once the case.

1.2.2 Prevalence of Psychological Problems

Physical illnesses are associated with an increased risk of experiencing psychological problems and disorders. People who are medically ill often have to endure debilitating treatments that can further contribute to this increased risk. Deterioration in quality of life and family functioning can also occur. The prevalence of psychological disorders among people with physical illnesses is higher than that seen within the general population (Chew-Graham & Hogg 2002, Martin 2001). These are most commonly adjustment disorders, anxiety disorders and affective disorders. Adjustment disorders occur in approximately one quarter of general medical patients and a further 12% of people experience symptoms of anxiety and depressive disorders (Feldman *et*

al. 1987; Mayou & Hawton, 1986). It is commonly accepted that prevalence estimates vary enormously (by as much as 40%) depending upon the strategies that are used to estimate the presence and severity of psychopathology. Studies that use self report measures of anxiety and depressive symptomatology tend to produce higher estimates than studies that use standardised diagnostic classification systems such as the International Classification of Diseases (World Health Organisation, 1992) and Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994). Researchers have sometimes failed to address the potential confounding nature of somatic symptoms. This has resulted in a similar tendency to overestimate the prevalence of psychological disorder. The capacity of physical ill health and associated treatment to precipitate posttraumatic stress reactions is being increasingly recognised. The prevalence of Posttraumatic Stress Disorder (PTSD) among those with medical illness might be as high as 25%, though this figure relates to patients discharged from intensive care (Tedstone & Tarrier, 2003). Prevalence rates for PTSD among people with cancer are likely to be around 5-10% (Kangas *et al.* 2002).

Depressive disorders occur in approximately one third of people with physical health problems and are more likely to occur in the presence of a life threatening illness or when the problems are part of a chronic course (Peveler *et al.* 2003). People who are exposed to treatment that is associated with unpleasant side effects (e.g., prolonged pain or changed appearance) and people whose physical illnesses occur in the context of social adversity or low social support are at particular risk of comorbid psychosocial morbidity with a predominant depressive component (Smith, 2003). These reactions may also

occur as a direct result of biological influences: the physical disorders themselves (e.g., a depressive episode mediated by thyroid dysfunction) or a medication induced phenomenon (e.g., an anxiety reaction related to corticosteroids).(Moore and Jefferson, 2004) Psychopathology among the physically ill is often not detected (van Hemert *et al.* 1993).

Developments in psychological medicine, clinical health psychology and liaison psychiatry are reflective of the widespread interest that has developed in acknowledgement both of the psychological consequences that can be the result of becoming physically ill and the changing patterns of disease. This acknowledgement of psychosocial correlates, consequences and contributors to the experience of physical illness is very clearly seen in the establishment and development in the 1970s of the clinical and academic specialty of psycho-oncology. This will be considered in the next section in greater detail to provide some background information within which the specific focus of subsequent chapters can be understood.

1.2.3 Psychological Adjustment to Cancer

1.2.3.1 Changing Patterns of Cancer Incidence

Cancer is a major cause of morbidity in the UK. It is estimated that around 2% (1.2 million people) from the UK population are living with cancer at any one time. For men, lung cancer is the most common diagnosis, followed by prostate cancer. Breast cancer is the most common cancer affecting women, followed by colorectal cancer and lung cancer (Cancer Research UK, 2002). Increasing medical advances have also meant that more people are cured of cancer than ever before. As a consequence, people with cancer are now tending to live longer than used to be the case (even when cancer treatment is being given without curative intent). These changing circumstances mean cancer is increasingly being conceptualised as a chronic illness. Cancer is a range of illnesses and diseases, each with a different aetiology, treatment regime and prognosis (Souhami & Tobias, 1998). Almost everyone who is told that they have cancer will experience a period of psychological distress. (Zabora *et al.* 2001) For some this will be a self limiting experience, one which does not cause any lasting psychological problems and which can be understood as part of a normal adjustment reaction. However, there are some people who will experience psychological problems that significantly interfere with their quality of life and ability to function on a day to day basis. (Allgar *et al.* 2003)

1.2.3.2 Prevalence and Nature of Psychological Problems in Cancer

It is generally accepted that around 20% of patients with cancer experience clinically significant psychological symptoms (Derogatis *et al.* 1983). Cancer treatment is also associated with a number of psychosocial concerns, some of which comprise quality of life and contribute to anxiety or depression. Non

physical treatment side effects such as anger, anxiety or apprehension are often rated by patients as being more severe than physical side effects such as nausea or hair loss (Coates *et al.* 1983). Indeed, some patients may drop out of chemotherapy because of psychological problems (Gilbar & Kaplan de Nour, 1989). Some treatment procedures (e.g., bone marrow transplantation) result in psychological problems because of the demands that they involve. Many patients have to face treatment regimes that are difficult to tolerate and may involve behavioural demands such as frequent hospital visits. Some treatments require levels of motivation that may be difficult to generate or sustain. Advances in drug therapies have resulted in a reduction in the incidence of nausea and vomiting associated with chemotherapy. However, conditioned nausea and vomiting do still occur and aversions to food or other elements of cancer experience can also develop (Morrow *et al.* 1992). Even after the end of treatment, patient's lives may be affected throughout the follow up period, as they attend appointments to determine whether the cancer has returned.

Research into psychological aspects of cancer has undergone what Montgomery (1999) has referred to as a 'mini renaissance'. Progress in cancer genetics has resulted in increased awareness of the possibility of negative psychological reactions to increased genetic predisposition for cancer (Cull *et al.* 1999; Hopwood, 1997). Researchers have examined the way in which patients manage uncertainty about this, make decisions about treatment (e.g., prophylactic mastectomy) and how, in some cases, beliefs about genetic risk of cancer can precipitate or mediate psychological problems. Cancer has also become something that has been raised in the public consciousness, assisted by a number of 'high profile' cases that have received

media attention and/or have been featured in newspaper or media publications containing reflections pertaining to experiences of living with cancer. These writings provide an insight into the range of thoughts that relate to how people make sense of and interpret their reactions to cancer. This raised awareness of cancer is very much a reflection of the increased acknowledgement of the importance of 'truth-telling' and open communication (Faulkener & Maguire, 1994).

Faulkener and Maguire (1994) have suggested that psychosocial adjustment to cancer is associated with six hurdles - managing uncertainty about the future, searching for meaning, dealing with a loss of control, having a need for openness, needs for emotional support and needs for medical support. The nature and extent of patient psychological problems will depend upon an interaction between factors such as prior cancer history, levels of social support (Devine *et al.* 2003; Holland and Holahan, 2003) and the precise nature of the patient's experiences of cancer. Patients psychological experiences will differ according to the nature of their cancer experiences and will depend on whether they are waiting for test results to confirm the diagnosis, attending for follow up or in the middle of a course of chemotherapy. Some psychological problems are more commonly experienced at particular times. This is most likely when the illness is diagnosed, during the early months of treatment, when all treatment has ended or when a recurrence or spread of the cancer is discovered. Some patients find that it is only after their treatment ends that they will notice any lasting negative psychological consequences (Arai *et al.* 1996; Ell *et al.* 1989). Most however will not experience any lasting negative psychological consequences, defined as the absence of clinically significant psychological or

psychiatric symptoms (Fobair *et al.* 1986; Gritz *et al.* 1988; Lesko *et al.* 1992; Wellisch *et al.* 1996). There are of course a number of other manifestations of longer term psychological impact that need to be considered. Some people will develop an increased vulnerability to future problems as a result of the psychological impact of cancer. The psychological effects of cancer and cancer treatments can result in patients becoming more avoidant in their thinking about illness, having greater illness concerns and diminished capacity to work (Cella & Tross, 1986). Cella and Tross (1986) provide a useful framework for understanding the stages which someone with cancer may pass through - they refer to the 're-entry to the premorbid lifestyle' for those people who have experienced cure or remission.

1.2.3.3 Psychological Therapies in Psycho Oncology

Psychological models of adjustment and principles for psychological management of the problems associated with cancer are now beginning to emerge. Most empirically validated psychological interventions for cancer related morbidity have been of short term, structured and problem focused nature (Devine & Westlake 1995; Meyer & Mark, 1995). Cognitive behavioural interventions and therapies have been shown to be effective when applied to the psychosocial issues and problems experienced by cancer patients (Fawzy *et al.* 1999, Meyer & Mark, 1995). Cognitive behaviourally based interventions such as adjuvant psychological therapy have been shown to improve anxiety and depressive symptoms (Greer *et al.* 1992) and be superior to supportive counselling (Moorey *et al.* 1998).

Supportive expressive therapy has been traditionally delivered in a group and in the context of work to evaluate the impact of participation in such groups

on survival. Based on the premise that most people tend to avoid the fear and anxiety associated with the possibility of death, supportive expressive therapy enables someone to express and tolerate the affect associated with thoughts of death and dying (Spiegel & Classen 2000). Kissane *et al.* (1997) have integrated elements of cognitive, supportive and existential therapies in their work to evaluate group therapies.

In the context of a growing interest in the effects of psychosocial factors on health and illness over the past two decades, there have been various attempts to examine the influence of psychosocial factors on mortality and the potential benefits of psychological intervention on survival. The well know work of Spiegel *et al.* (1989) of metastatic breast cancer group members that found significantly longer survival time (36.3 months for group members vs. 18.9 months for no-treatment controls) led to a great deal of interest in the effect of group social support on morbidity and mortality. Studies of the effect of group interventions on these variables are inconsistent, with some showing improved survival time and immunologic response for cancer group members (Fawzy *et al.* 1993; Spiegel *et al.* 1989), but others failing to demonstrate such a connection (Cunningham *et al.* 1998; Edelman *et al.* 1999; Goodwin *et al.* 2001; Ilnyckyj *et al.* 1994; Schrock *et al.* 1999). Further research to address these issues has been carried out (Cunningham & Edmonds 2002; Kissane *et al.* 2001). Watson *et al.* (1999) have demonstrated that high helpless/hopelessness scores on the Mental Adjustment to Cancer Scale are associated with a moderately detrimental effect on survival. It is possible that psychotherapy targeted at helplessness and/or hopelessness might produce survival benefits.

Although psychological interventions from a range of modalities and traditions have been evaluated in cancer, it is cognitive behaviourally based work that has provided the impetus for the exploration of thoughts and images associated with cancer experiences (Manson *et al.* 1993) and informed research into cognitive processes in disorders such as depression (e.g., Brewin *et al.* 1998) among people with cancer.

1.3 Understanding Psychological Adjustment to Physical Illness

A range of factors is known to be associated with the occurrence of psychosocial morbidity in the context of physical illnesses. Information will be presented on these to provide the context for considering work that has sought to examine the psychological contributors to understanding the nature of and variability in adjustment to physical illness.

Patients who have high levels of trait neuroticism are known to be at a great risk of experiencing psychological problems in the context of physical illness. (Deary *et al.* 1997). One of the most influential models within psychology on adjustment to physical illness has been that of Lazarus & Folkman (1984). They emphasised the importance of appraisal of the degree of illness threat and the secondary thoughts relating to the personal resources available to address this. Elements of this model can be appreciated in distinctions that are made between different levels of meaning within theoretical models that have been proposed (to be considered in Chapter 2).

Researchers have also examined a range of factors and variables within the overall theme of cognitive representations associated with physical illness

experiences. Some of these will be outlined to provide the background to later sections of this chapter that then focus on a very specific element of cognitive representation (i.e., meaning). The variation in the ways in which patients make sense of and respond to illness has been examined according the self-regulation model of Leventhal (Leventhal *et al.* 1992). This emphasises the importance of the illness representation held by the patient (Weinman *et al.* 1996). These are often disease specific in nature and as such components of illness representations tend to relate differently to adjustment and quality of life depending upon the nature of the disease process (Heijmans & de Ridder, 1998). It has been shown that the illness representation held by the patient can account for variations in emotional reactions to symptoms (Prohaska *et al.* 1987) and self care behaviours (Petrie *et al.* 1996). Patients with more negative views of their illness are more likely to be depressed (Murphy *et al.* 1999). Patients who view their illnesses as more serious, chronic, and uncontrollable tend to be more passive, report more disability, have poorer social functioning and more mental health problems (Heijmans, 1999). Patient perceptions of control over their symptoms and/or the course of their disease often relate to mood states such as depression (Affleck *et al.* 1987; Devins *et al.* 1981; Helgeson, 1992; Thompson *et al.* 1993). Perceived control has also been shown to predict recovery from disability (Johnston *et al.* 1999). Much work has been done to understand the influence of perceived control on physical and psychological health. Perceptions of enhanced control are generally regarded as being beneficial to those experiencing adverse life circumstances (Helgeson, 1992; Reed *et al.* 1993; Thompson *et al.* 1993). This is also known to be the case even when the perceptions of enhanced control are not realistic.

Thompson (2002) has suggested that this benefit is lost when such perception leads to the avoidance of actions that would be health promoting. This has been shown in laboratory tasks (Alloy & Clements, 1992) and clinical populations (Taylor *et al.* 1984). Optimism (the extent to which someone believes that future outcomes will be good or bad) is associated with more positive adjustment in the context of physical ill health and the use of more positive, problem focused coping strategies relating to the experience of physical illness (Carver & Scheier, 2002). Self efficacy has been shown to influence the occurrence of health promoting behaviour, the reduction of harmful actions and to be associated with the maintenance of behaviours such as exercise or alcohol abstinence (Maddix, 2002).

Work that has looked at factors related to variations in psychosocial adjustment to illness from a range of perspectives, although characterised by some differences about what is important, shares the common emphasis in that each seeks to outline how someone 'makes sense' of their physical illness experience. The range of psychological factors that have been suggested as important in considering adjustment to physical illness is a reflection of the growing interest in this element of understanding illness experiences. Although the changing pattern of disease referred to earlier is likely to have contributed to this interest, it should be acknowledged that work to understand how people make sense of their experiences is not new, nor restricted to the discipline of psychology. Before examining meaning in contemporary cognitive theory applied to clinical health psychology, the wider historical context within which the personal meaning of physical illness has been conceptualised will be considered. This will then be followed by

more detailed consideration of the different foci of meaning that can be appreciated within the psychological literature. The chapter will then conclude by summarising how this wider context of work on meaning as a construct might relate to understanding the psychosocial dimension of physical illness. This will signal the introduction of a need for more careful consideration of processes and levels of meaning within this work.

1.4 Meaning and Psychosocial Adjustment

1.4.1 Meaning from a Philosophical and Spiritual Perspective

The way in which people make sense of their lives has been the subject of study within other disciplines such as philosophy and religion. Schwartzberg (1993) has suggested that the need to establish meaning or purpose is a thread that runs through what he refers to as the "humanist-existentialist psychological literature". The existentialist position is that life is not automatically something that is associated with particular meanings but that individuals are actively engaged with the process of constructing this. Feifel (1959) suggested that attempts by humans to attempt to find meaning when confronted with negative events is one of the unique and defining elements of human experience. Doka (1997) has suggested that spiritual and philosophical systems of beliefs provide the building blocks for the quest for meaning. Prager (1996) has stated that "personal meanings drive and/or are driven by the themes people create, by which they interpret and evaluate their life experiences, attempting to integrate their life experiences, attempting to integrate them so as to form a self concept" (p. 119).

It has long been recognised that exposure to adversity can "provoke nagging questions about life's meaning and purpose" (Burris *et al.* 1996). Meaning is

at the heart of the theories of Victor Frankl (Frankl, 1997), believing as he did that as a construct it is highly integrated with the human condition. Indeed this was central to his autobiographical account of his time within a Nazi concentration camp. Burris *et al.* (1996) refer to an "existential struggle borne out of confrontation with tragedy and conflict".

Davis and Nolen-Hoeksema (2001) have referred to this process as having a compulsive quality, relating to a desire to imbue events with meaning or purpose borne from an innate need to 'make sense' of such events. The process of ascribing meaning to life experiences following exposure to trauma has been widely researched with a range of populations, ranging from holocaust survivors to people who have lost limbs. This 'quest' for meaning is also commonly referred to a 'struggle' or 'search' for meaning (Tasker, 2003). The potential complexity is reflected by the fact that reactions to adversity can result in people having to 'make sense' of the fact that the event occurred but also of the mental consequences of their reactions to the event. This latter element may involve the loss of a belief system that had previously supported an individual person's sense of wellbeing.

Factors that provide a sense of meaning to individuals has been explored from a lifespan perspective where work has shown that people tend to derive meaning from a similar range of sources across their lives (Reker, 1996). Here too it can be seen that the search for meaning can be appreciated as a common thread running through work that has considered philosophical and spiritual perspectives.

1.4.2 Search for Meaning and Physical Health

The phenomenology of the psychology of meaning can be confusing, Langle (1993) has suggested that the term has chameleon qualities in that "What is meaningful for one person may lack meaning for the other or may be meaningful for the same person at one time and meaningless at another" (p.42). Within psychology, it is possible to appreciate themes in the way in which meaning has been understood and studied.

Meaning has been viewed from three perspectives. The first perspective is based on the observation that some patients find the experience of physical illness to be traumatic (the extent to which this is true is of course variable across patients and illnesses) and this traumatic experience has an impact on their thinking about themselves and their world. The impact of traumatic elements on meaning could of course have a different impact depending upon the precise way in which meaning has been understood and defined. This is a theme that will be addressed in Chapter 2. A second psychological perspective on meaning has been to consider it as a component of wellbeing. Here it is assumed that the possession of some elements of meaning (however this is defined) is a necessary element of what constitutes psychological wellbeing. Finally some psychologists have suggested that meaning can be used as a discrete coping strategy (Folkman, 1997).

All of these are theoretically possible and there are scenarios when the process and outcome of an individual person's psychological reactions could be more readily understood by thinking of meaning in the manner suggested. These suggestions on the way in which meaning might be applied in clinical health psychology will now be considered.

It is now well accepted that the process of creating meaning in adjusting to trauma is of fundamental importance in understanding adjustment. Doka (1997) suggests that "questions of meaning" will differ in accordance with the different phases within an individual experience of illness. Acute illness involves patients having to incorporate the reality of their illness experience into their life view of past and future. Questions of meaning relating to chronic disease are proposed to be more associated with understanding suffering. With incurable disease the emphasis becomes focused upon finding meaning in life and death. Lipowski (1970) has outlined eight illness concepts that he suggests capture "the individual personal meaning of and attitude towards his illness, injury or disability". These are described as illness as challenge; illness as enemy; illness as punishment; illness as weakness; illness as relief; illness as strategy; illness as irreparable loss or damage and illness as value. Using Lipowski's framework, Schussler (1992) examined the relationship between individual meanings and coping strategies used by a group of patients, the majority of which had chronic diseases and the remainder with a variety of 'psychosomatic diagnoses'. Janoff-Bulman (1989) was one of the first to begin to explore personal construal of meaning and the relationship to adjustment in a physically ill population (in this case, people with spinal injuries). She found that blaming another person and believing that one could have avoided the accident predicted poor coping. Participants exhibited a "need for meaning" in explaining the occurrence of the accident that resulted in their spinal injury.

These processes have also been implicated in understanding the links with coping strategies adopted following physical illness. Folkman (1997) examined

the relationship between positive and negative psychological states and the coping strategies employed by caregivers of people with AIDS diagnoses. One of the coping processes that she observed was labeled as ".. the infusion of ordinary events with positive meaning". She also outlined how the different coping strategies that were associated with positive psychological states shared the common underlying theme that related to "searching for and finding positive meaning" (p.1215).

Although meaning has been considered as an antecedent to psychological wellbeing, a factor influencing coping response and a coping response in its own right, Ryff (1989) has suggested that 'purpose in life' is a core dimension of what constitutes psychological wellbeing. The other component dimensions are self-acceptance, positive relations with others, autonomy, environmental mastery and personal growth. The construct of meaning is implicated within this multidimensional model of psychological wellbeing. Ryff (1989) has suggested that purpose in life is related to "beliefs that give one the feeling that there is purpose in and ***meaning*** to life ..... thus one who functions positively has goals, intentions and sense of direction all of which contribute to the feeling that life is ***meaningful***" (p.1071, emphasis added).

Confusion is often apparent within literature on meaning, particularly when it is not clear what focus individual researchers are adopting. However, finer discriminations are beginning to appear within the literature on the precise content of meaning that is associated with illness experiences. It is also possible to appreciate a greater emphasis on attempts to examine positive and negative elements of meaning. Affleck and Tennen (1996) emphasise the pivotal role that has been afforded to what they refer to as "the search for

uplifting meaning from threatening experiences" in a range of psychological theories about psychological adjustment following exposure to traumatic events. This often includes reporting of strengthened relationships, positive changes in personal characteristics such as tolerance or empathy and modifications to life goals and priorities.

Positive meaning has been studied across a wide range of physical disorders. This phenomenon is related to a number of positive psychological outcomes in terms of less negative affect, distress and intrusive thoughts. Construal of benefits during the early phase of exposure to medical illness may be predictive of later psychological adjustment (Affleck *et al.* 1987; Affleck *et al.* 1991). Sears *et al.* (2003) have provided a useful distinction between benefit finding, positive reappraisal coping and post-traumatic growth. Here they outline how the identification of a benefit would only lead to the use of positive reappraisal coping if there were an active attempt to utilise this realisation in the way that implied a coping response. The perspectives referred to above are easily confused and here Sears *et al.* (2003) have outlined how benefit finding might be an example of the end point within a process of adjustment to the trauma of physical illness and have highlighted how the presence of benefit finding does not necessarily equate with the use of such information as a coping strategy. It is clear that the boundaries between benefit finding, positive reappraisal coping and posttraumatic growth need to be examined further.

1.5 Conclusions

As the prevalence of physical illnesses has changed over the past several decades so too has the number of researchers that have examined psychosocial aspects of adjustment to living with a physical illness. The potential of physical illness to cause psychological morbidity is well recognised and a range of factors have been identified to account for variability in levels of adjustment. This Chapter has outlined the specific issues relating to psychosocial aspects of cancer. Work that has outlined the importance of cognitive models and factors has been outlined. It has been argued that this reflects a common thread not only within clinical health psychology but also within philosophy and religion toward understanding the significance of meaning as an important and pivotal explanatory construct. The Chapter ended with an overview of the differing ways in which meaning has been studied within contemporary cognitive health psychology. These different perspectives focus on the way in which meaning might fit within psychological models. In some it is viewed as an antecedent to other factors (e.g., the application of a coping strategy). Some have considered meaning to be a coping strategy in its own right or the outcome of a process of adjustment.

Chapter 2 Psychopathology, meaning and its application to cancer

2.1 Overview

Meaning as a construct can be conceptualised as having a different place within psychological models of adjustment to illness (antecedent variable, coping strategy, dimension of wellbeing, etc.). There are also a range of ways in which it can be defined when considered in isolation. This Chapter will consider aspects of meaning that relate to how it can be understood as a stand-alone construct. This is outlined within the broader context of psychopathology, and considered specifically with cognitive models and constructs in understanding adjustment to physical illness. Important distinctions in considering meaning will be suggested and discussed in relation to psychosocial adjustment to cancer.

2.2 Introduction

Meaning is defined in the Oxford English Dictionary as 'that that conveys or expresses meaning or thought; expressive, significant' and '.... The signification, sense, import; a sense, interpretation'. Despite the widespread application of work to examine meaning that was referred to in the previous chapter, the academic study of the various facets and levels of meaning within clinical psychology has been characterised by considerable degrees of conceptual and semantic confusion.

2.2.1 Psychopathology and Meaning

It has been suggested that meaning may be the common pathway by which all psychological therapies have their influence on underlying psychopathological processes and products. Indeed, Power and Brewin's (1997) edited textbook

consists of a series of chapters each containing a different account of the ways in which the construct is relevant to understanding how meaning is transformed during psychotherapy and the ways in which the construct can be applied to understanding psychopathology.

It is well established that the individual meanings ascribed by people to elements of their life experience are crucial in understanding the nature and extent of psychological distress (Brewin & Power, 1997). Cognitive content (of which meanings are a component) varies according to the different diagnostic groupings being studied (Matthews, 1997). Physical sensations that are characteristic of autonomic arousal and are viewed as meaning that there will be an impending medical emergency (e.g., myocardial infarction or syncope), lead to the range of behaviours and experiences collectively outlined in the diagnostic criteria for panic disorder (American Psychiatric Association, 1994). Many experimental investigations have confirmed that depressive symptoms are accompanied by negative meanings and interpretations concerning helplessness and hopelessness (Matthews, 1997).

Issues of meaning form a central component of most forms of psychopathology in that it is usually the presence of unwanted or painful meaning or the absence or loss of meaning (Janoff-Bulman, 1992) that mediates or moderates psychosocial problems. In some cases the ways in which the occurrence of thoughts and meanings are understood (e.g., signs of madness) or processed is important (Wells, 2000b). Although, the meanings ascribed to experiences differ markedly between individuals, they can share commonalties that can be expressed as themes (e.g., thematically related to threat). These can be used to guide research and clinical work. Specific meanings may be associated with

one or more of these themes (e.g., the thought that someone is no longer a complete person as a result of cancer could be thematically related to loss and also to self esteem). This notion of the significance of discrete meanings is of course central to cognitive therapy. It has been emphasised even more within work on understanding the ways in which people assimilate traumatic experiences into their pre-existing beliefs about the world (i.e., the occurrence of re-experiencing phenomena as the result of a failure to reconcile traumatic experience with premorbid global meanings), (Greenberg, 1995).

2.2.2 Cognitive Therapy and Meaning

The seminal work on Cognitive Therapy of Depression (Beck *et al.* 1979) stated that

"We are self determined by the meanings that we give to our experiences ... Meanings are not determined by situations, but we determine ourselves by the meanings that we give to situations" (Beck et al. 1979 pp8-9.)

Here the notion of meaning is central to the conceptualisation that underpins the early work on cognitive therapy of depression. Moss (1992), referring to this work believes that developments within Beckian cognitive therapy have legitimised questions relating to consciousness, meaning and 'personal experiencing':

"His cognitive therapy is a clinical discipline devoted to assisting depressed and anxious patients in their personal struggle for ***meaning****. (emphasis added) Beck does not pretend to be a philosopher or to present a*

philosophically adequate theory of consciousness or meaning. Nevertheless, his discussions of emotional disorders and therapeutic interventions make continuous reference to the "meaning of meaning", the distinction between public and private meanings, and the individual attribution of meaning. An implicit philosophy of consciousness, experience, and meaning can be read between the lines." (p.89)

The notion of understanding the meaning ascribed to experiences is most clearly seen in the questioning that is often applied during the guided discovery process of cognitive therapy - 'What did that mean to you?', 'You say you feel worthless, what does that mean for you personally?'. Clinical psychology has become increasingly cognitive in emphasis (Rachman, 1998) and Beckian approaches to cognitive therapy have come to predominate mainstream clinical psychology within the UK. This emphasis can also be seen in the development of cognitive conceptualisations and therapies, where the cognitive model has been applied to understanding psychological factors in physical health and not simply psychiatric disorders (e.g., Tuschen-Caffier *et al.* 1999). In recent years there has been an increasing emphasis upon the application of cognitive theories to understanding patient experiences of physical illness. Clinical cognitive theorists and therapists now accept that there is a need to examine in greater detail the individual meanings given to an illness by an individual if we are to refine cognitive models of adjustment to illness.

In cognitive theory and therapy meaning is central to the original elements of the cognitive model and can be appreciated in more recent models of disorders such as PTSD (Ehlers & Clark, 2000). Irritable bowel syndrome

(Greene & Blanchard, 1994), chronic pain (Morley *et al.* 1999) and cancer (Greer & Moorey, 1997) have all benefited from the publication of empirically validated cognitive treatment protocols. The themes that are apparent within the general health psychology literature on meaning have been applied to understanding the experiences of patients with cancer (Lewis, 1989; O' Connor *et al.* 1990). Meaning is becoming an increasingly important construct within applied psychology. The study of meaning as a construct and process of relevance in the assessment and management of psychopathology, the preponderance of cognitive theories and therapies within clinical and health psychology and, related to this, the specific application of meaning to work within health psychology all support the need to examine the relevance and boundaries within this construct in greater depth. Here, the influence of cognitive models on psychological therapy development has tended to mirror the growing interest on cognitive models of adjustment to physical illness.

2.3 Conceptualisations of Meaning

Most authors seem to agree that the study of meaning involves analysis of cognitive activity and that this relates to processes by which individuals make sense of their experiences on various levels. However, there has been less agreement with regard to the precise elements that comprise this 'sense-making' process. This is reflected in the fact that the term 'meaning' has been and is often used in different ways. The three most common ways in which meaning is studied are first, to refer to discrete, situation-specific interpretations; second, the processes by which an individual endeavours to assimilate experiences into a pre-existing belief structure ('search for meaning') and finally, as the final outcome of a psychological process (i.e., meaning is found). These differing uses of the term will now be outlined.

2.3.1 Different General Uses of the Term 'Meaning'

'Meaning' has been used to refer to the discrete interpretations that may be assigned to an internal or external stimulus. An example of this might be someone who, following exposure to exercise, believes that their increased heart rate means they will have a heart attack. The term has also been used to refer to the process of making sense of life events. A person who reports that they cannot make sense or find any meaning following a traumatic car accident illustrates this. The importance of understanding meaning, and particularly meaning about issues such as orderliness and purpose in life with regard to adjustment to traumatic life events has been given greater impetus by a proliferation of theories that PTSD is more likely when life events lead to the disconfirmation of basic beliefs in a personal theory of reality (Janoff-Bulman, 1992). With the use of the term 'meaning' to refer to the eventual outcome of a psychological process, meaning is something that is attained or not.

2.3.2 Global or Situational: Different Levels of Enquiry

In addition to the differing emphasis on phenomenological components of this construct, reference to the 'level' of meaning being considered has also differed in focus. In some cases global beliefs are referred to and in other work more situation or context specific interpretations of experiences are addressed. Global references to meaning tend to encompass beliefs about global or cross-situational issues, the benevolence of the world or faith. The task of 'finding meaning' in the midst of adverse experiences has been examined within such a global perspective. Park and Folkman (1997) have differentiated global from situational meaning. Global meaning has been

defined as the basic goals and fundamental assumptions, beliefs and expectations about the world. This has been operationalised in a number of ways. Sense of coherence (Antonovsky, 1993) is an example of one of the ways in which this has been operationalised. It consists of dimensions that relate beliefs about order and also with life goals and purpose and is an example of a global meaning construct.

Situational meaning relates to the interaction between global beliefs and goals and the circumstances of a particular person-environment interaction. This term is more situation specific, linked with discrete appraisals, interpretation and beliefs and is the end point of a process where global meaning influences situational meaning content.

2.3.3 Semantic Confusion

The semantic confusion that has been alluded to is seen in the varying operational definitions that have been used in the study of meaning. Contributors to this literature have operationalised meaning in seemingly indistinct ways and have considered situational and global meaning components as if these are the same. Coward and Wilkie (2000) refer to the discrete interpretations of their patient sample but later talk of "....activities that previously gave them pleasure and meaning" (p.107). This illustrates confusion in the use of the term to refer to a discrete interpretation of an internal stimulus (in this case pain) and then later to refer to the outcome of a process.

Despite the differing conceptualisations of meaning within the literature, most would agree that there are dynamic elements within the process of

meaning making and that the discrete results differ over time. Events that are judged negatively in the immediate stages after their occurrence can come to be viewed differently with the passage of time. Almost a third of the participants in the study by Catlin and Epstein (1992) reported that events originally viewed as having a destructive influence were later viewed in terms of having a net positive effect. Tomich and Helgeson (2004) reported that the experience of particular components of positive meaning has been shown to have a different relationship with distress according to the way in which positive meaning is experienced and the time that distress is assessed. They also found that among women with breast cancer benefit finding was associated with negative affect at baseline and that greater benefit was reported in those with more severe disease. Davis *et al.* (1998) examined the role of sense making and benefit finding in adjustment to bereavement. They found that sense making was associated with less distress within the first 12 months following bereavement and that benefit finding was associated with less distress at 13 months and 18 months following bereavement.

2.3.4 Park and Folkman's Conceptualisation of Situational Meaning

Park and Folkman (1997) have suggested that situational meaning consists of three components. First, the interpretations made by individuals regarding the personal significance between the person and the environment. These are the interpretations which determine the extent and nature of distress experienced by someone in response to the particular person-environment interaction being considered (as outlined at section 2.3.2). Second, they outline the meanings that are representative of the search for meaning that takes place when a situation or person-environment interaction has been appraised as distressing. This component of their conceptualisation of

meaning is most closely linked with the secondary appraisal component of the coping model of Lazarus and Folkman (1984) referred to when the coping perspective was being considered in Chapter 1. Finally, they suggest that meanings are made in the aftermath of an event and it is this that they refer to in terms of meaning being an outcome, a reflection of the interactions that take place in their model between global and situational components.

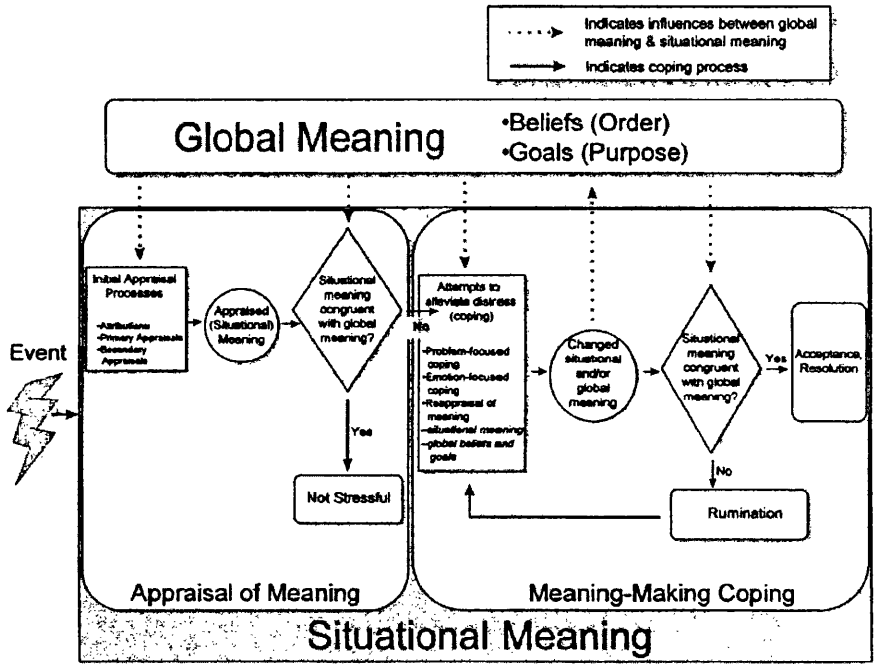


Figure 2.1 Park and Folkman's Model Relating Situational and Global Meaning (Park & Folkman, 1997) (p.117)

2.3.5 Meaning from Multiple Perspectives

Meaning then can be thought of as an interpretation, process or outcome. It can be thought of at situational or global level and, as was outlined at section

1.4.2, considered at different stages within models of psychological adjustment (antecedent, moderator or coping strategy).

Review of the ways in which others have conceptualised meaning illustrates how the study of meaning has been characterised by work that has emphasised the phenomenological elements (discrete interpretation, psychological process or outcome) and the level of analysis (global or situational). Some studies have examined discrete interpretations relating to world views following a traumatic stressor (i.e., interpretations with a global emphasis), others have examined the outcome of a search for meaning and its relationship to adjustment (outcomes with a global emphasis). Others have looked at the specific thoughts that are associated with a failure to attain a purposeful meaning (outcomes with a situational emphasis). A diagrammatic representation outlining two of these levels of discrimination is outlined at Figure 2.2. This figure also summarises the different ways in which the overall construct might fit within psychological theories of adjustment to physical illness. The potential relevance of meaning to psychosocial oncology research will now be examined.

2.3.6 Meaning is not Synonymous with Coping or Adjustment

There are similarities between the psychological constructs of meaning, coping and adjustment. Each construct is complex, multidimensional and can be understood in terms of relationships with environment, personal resources, disposition and emotional regulation.

Folkman and Moskowitch (2004) have defined coping as being the thoughts and behaviours that are used to manage the internal and external demands of situations that are appraised as stressful. Although this definition makes it clear that there is an active attempt to utilise thoughts in the management of demands (not something that is an integral part of meaning), "The difference between appraisal of the situation, coping itself and the adjustment which is presumed to result from coping behaviour, is often difficult to establish" (p. 338) (Moorey et al 2003). Adjustment can be thought of as a state that can be represented by the absence of psychological morbidity, a process by which change occurs between psychological states or as being a point that has to be reached at the end of a process (Brennan, 2001). Watson et al (1988) have define adjustment as the "cognitive and behavioural responses that the patient makes in response to cancer" (p. 204). Although adjustment contains behavioural and cognitive dimensions this definition potentially confused coping by using terms such as "responses" and "making" which imply and element of volition of the sort seen in definitions of coping.

An individual might outline the way in which the predominant meaning experienced in relation to their cancer is that "Cancer rules my life", this might be associated with a tendency toward avoidant thinking and that this in turn leads to problems of adjustment that are characterised by intrusive thoughts and anxious mood. Here it is possible to appreciate that meaning, coping and adjustment are discrete components of an overall psychological process.

2.4 Meaning and Adjustment to Cancer

Cancer challenges people's views of the world as meaningful, purposeful and coherent - 'what it all means' is a common focus of thinking. Meaning as a process concerned with the integration of experience with global beliefs has been examined with cancer patients. Coward (1997) has suggested that the experiences associated with cancer result in 'severe spiritual disequibilrium' and that the process of searching for meaning is a response to this state. Lepore and Helgeson (1998) suggest that "integrating the cancer experience into (their) pre-existing mental models should promote psychological adjustment". O'Connor *et al.* (1990) defined the process of searching for meaning as " ... *questions about the personal significance of a life circumstance, such as cancer, in order to give the experience purpose and to place it in the context of a total life pattern; ....*". Patients concerns about why they should have developed cancer (the 'why me' issue) are often cited as being prevalent among the range of concerns experienced (Faulkener & Maguire, 1994).

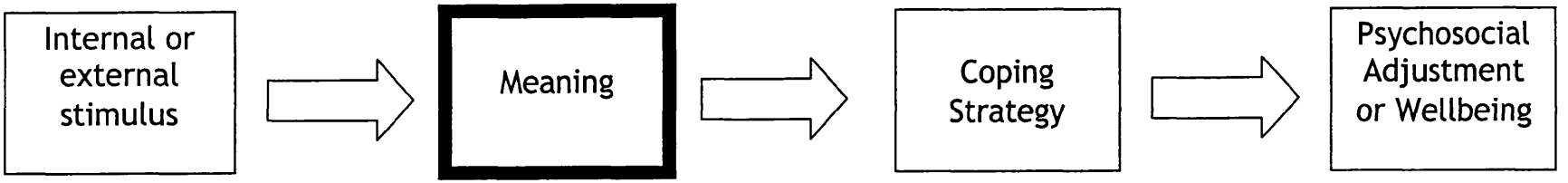
Psychosocial oncology, as with clinical psychology, has become increasingly cognitive in emphasis. Researchers have examined issues such as symptom perception (Cameron *et al.* 1998) and intrusive memories and their relationship to depressive symptoms in cancer patients (Brewin *et al.* 1998). Cancer is associated with a number of discrete threats and losses. It is well recognised that a substantial proportion of people with cancer experience psychological distress and morbidity associated with their cancer experiences (Derogatis *et al.* 1983; Hopwood *et al.* 1991) and that psychological morbidity is two to three times higher than that found in the general community (Bloch

& Kissane, 2000). Understanding the personal meaning of the disease for patients is crucial to appreciating the mechanisms underlying cancer related distress (Greer & Moorey, 1997).

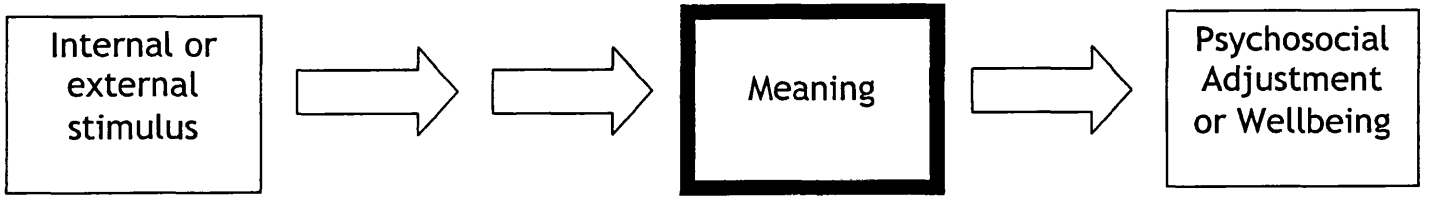
2.4.1 Situational Meaning and Cancer

The precise nature of the content and processes giving rise to the meanings and interpretations of cancer patients have been subject to much speculation in the literature. It has been suggested that the preservation of self esteem, maintenance of a perception of justice and the achievement of control are likely to be the main determinants of the specific meanings attached to the cancer experience (Turnquist *et al.* 1988). Therefore, meaning is a concept that has relevance from a number of perspectives in understanding the psychology of cancer. However there have been a number of problems associated with the work of those who have sought to examine meaning. In common with the literature in general and as already mentioned, is has been poorly understood, defined and operationalised. Parle *et al.* (1996) found that it was not the existence of cancer related concerns that was predictive of later affective disorder but that it was the associated interpretations (i.e. the discrete meaning attached to the experience of the concern) that were predictive of later affective disturbance. Barkwell (1991) found that the meaning ascribed by patients with advanced cancer to the experience of pain was significantly associated with pain experiences, depressive symptoms and coping strategies. This supports the earlier suggestion of the relevance and importance of understanding the way in which patients think about their cancer experiences. This is an example of the concept of meaning being applied to understand discrete context specific issues (ie interpretations at the situational level). This has also been examined in studies to understand

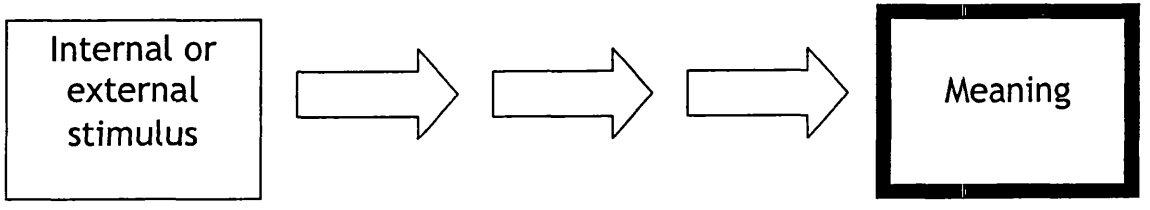
A Meaning as determinant of coping strategy applied

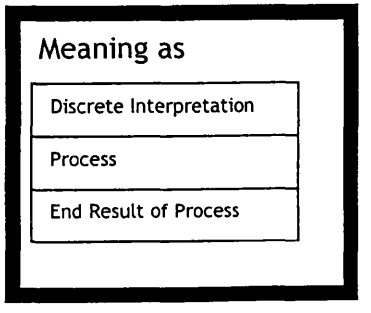


B Meaning as a coping strategy



C Meaning as a component of wellbeing





Within each possible model, meaning includes different elements.

Figure 2.2 Visual Representation of (1) Role of meaning within differing theories and (2) components within this construct.

the meaning of pain as experienced by patients with advanced cancer (Coward & Wilkie, 2000; Ferrell *et al.* 1993) and the way in which the meanings of being a nurse in cancer care can impact upon job satisfaction and performance (Cohen 1995)

2.4.2 Global Meaning and Cancer

There have been some attempts to understand the influence of global meaning on adjustment to cancer. Johnson-Vickberg *et al.* (2000) examined the links between global meaning and distress among bone marrow transplant patients. They reported that global meaning was associated with greater distress (in general and related to the bone marrow transplant) and quality of life variables. In a study of breast cancer patients Johnson-Vickberg *et al.* (2001) demonstrated that global meaning moderated the relationship between the presence of intrusive thoughts and psychological distress. The possible clinical applications of work into global meaning and psychosocial oncology are also being recognised, explored and used to develop new psychotherapeutic approaches for people with cancer.

Greenstein and Breibart (2000) have been developing a group psychotherapy approach for people with cancer based on the concept of meaning and the search for meaning. There has also been increasing recognition of the importance of enabling cancer clinicians to appreciate the relevance of meaning related phenomena to their clinical practice. Foster and McLellan (2000) suggested that cancer care professionals should endeavour to assess the meaning derived from a person's cancer experience (global meaning) and that this can lead to clarification or challenging of misappraisals (of more relevance to situational meaning). Greenstein and Breibart (2000) and Gil and

Gilbar (2001) have suggested that counteracting negative information about cancer can be achieved by cognitive behaviour therapy and that this in turn maintains a schema of hope.

2.5 Working Definition of Meaning

The definition of meaning that will be used within this work is that meaning relates to the thoughts and beliefs that are reflective of the interaction between cancer and individual's personal environment and which relate to the circumstances of an individual person-cancer interaction. These thoughts and beliefs are specifically focused on cancer, are not global thoughts about the world but are instead more in keeping with what Folkman describes as situational meaning elements.

2.6 Conclusions

Meaning has been identified as a pivotal concept within cognitive therapy and in understanding mediators of psychopathology. Different definitions have been used, focusing upon global or situational perspectives; emphasising meaning at various stages within a sequence of variables such as coping and wellbeing and discriminating interpretations, processes and outcomes.

Despite the clear relevance of the construct of meaning to understanding adjustment to cancer, psychometric assessments of the impact of interventions in psychosocial oncology have not always been sensitive to the potential that exists to impact upon meaning, particularly from a positive

perspective. There are therefore opportunities to develop the measurement of these cognitive aspects of psychological adjustment to cancer. Understanding meanings associated with cancer experience will be crucial in developing assessment protocols but also in refining guidance to practitioners working with people who have cancer. In order to do this, researchers must be able to reliably and validly assess constituent components of meaning. In addition to extending our understanding of this concept, the development of a short way of assessing meanings may be of use to cancer physicians and nurses who are not always sure how to access aspects of psychological experience. The next Chapter will focus upon considering currently available methods of assessing meaning in general and as applied to cancer.

Chapter 3 The Need for a Measure of Cancer Specific Situational Meaning

3.1 Overview

3.2 Review of Assessment Measures of Meaning

3.2.1 Purpose of Life Test (PIL Test) (Crumbaugh & Maholik, 1964)

3.2.2 Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing Scale (FACIT-Sp) (Peterman *et al.* 2002)

3.2.3 Life Orientation Test (LOT) (Scheier & Carver, 1985)

3.2.4 Life Attitude Profile - Revised (Reker, 1992)

3.2.5 Sources of Meaning Profile - Revised (SOMP-R) (Reker, 1996)

3.2.6 Sense of Coherence Scale (Antonovsky, 1993)

3.2.7 Meaning in Suffering Test (Starck, 1983)

3.2.8 World Assumptions Scale (Janoff-Bulman, 1989)

3.2.9 Illness Cognitions Questionnaire (Evers *et al.* 2001)

3.2.10 Life Evaluation Questionnaire (Salmon *et al.* 1996)

3.2.11 Constructed Meaning Scale (Fife, 1995)

3.2.12 Other Meaning Assessment Methods

3.3 Discussion and Conclusions

3.1 Overview

Despite the increased acknowledgement of the importance of understanding dimensions of meaning and adjustment to physical illness, the recent work to consider meaning in relation to adjustment to cancer and the longstanding tradition within psychosocial oncology on the development and application of self-report assessment measures, there are few measures that assess dimensions of meaning from a cancer specific perspective. Self-report measures that are most commonly used are those that focus upon the presence of psychological symptoms, commonly occurring physical symptoms such as fatigue, quality of life and coping strategies.

The Mental Adjustment to Cancer Scale (Watson *et al* 1988) and Cancer Coping Questionnaire (Moorey *et al* 2003) have been developed to assess coping in response to a diagnosis of cancer. As previously outlined at section 2.3.6 coping and adjustment are closely linked with meaning. Some definitions of coping and adjustment include meaning as an element but they are sufficiently discrete constructs to be distinguishable, particularly when it comes to consideration of measurement and assessment. Although the MAC Scale and the Cancer Coping Questionnaire are important within psychosocial oncology the focus of this chapter will be on measures that seek to assess dimensions of meaning and not those that might refer to meaning as it has been conceptualised within the literature on coping.

Clinicians working in psychosocial oncology do not have reliable or valid ways of measuring important aspects of cancer related meaning. There are however a number of measures available that assess elements of meaning, though most have not been developed with people who have cancer and many have not been adequately researched in the context of understanding the psychosocial experiences of people with cancer. This chapter will examine the assessment and measurement of meaning within clinical and health psychology in general, focusing on issues such as the purpose, target population, development, administration, scoring, interpretation, psychometric properties, clinical utility and research applicability of the measures that will be considered. It will be argued that there is a need for a measure to focus upon cancer specific meaning dimensions.

3.2 Review of Assessment Measures of Meaning

Measures that contained items relating to global or situational meaning were identified by conducting Medline and PsycInfo searches using 'meaning', 'psychology' or 'cancer' as keywords and reviewing the measures that were used by researchers in the studies that were identified. Visual inspection of the contents pages of journals such as 'Psycho-Oncology', 'Journal of Psychosocial Oncology' and 'Health Psychology' also assisted in identifying studies that had used measures of meaning and related constructs.

Table 3.1

Overview of Measures of Meaning Considered in this Chapter

Purpose in Life Test
Functional Assessment of Chronic Illness Therapy
Spiritual Wellbeing Scale
Life Orientation Test
Life Attitude Profile - Revised
Sources of Meaning Profile - Revised
Sense of Coherence Scale
Meaning in Suffering Test
World Assumptions Scale
Illness Cognition Questionnaire
Life Evaluation Questionnaire
Constructed Meaning Scale
Other Meaning Assessment Methods

The following section will examine self-report measures of meaning (global and situational). Each questionnaire will be considered with regard to the purpose and background of the measure, the items that are contained within the measure, pertinent detail regarding elements of administration, normative data, scoring procedures and quality. The psychometric properties will be summarised and this will be linked to the clinical utility and future research needs regarding the measure being considered. Measures of global meaning will be considered first and measures of situational meaning thereafter.

3.2.1 Purpose in Life Test (PIL Test) (Crumbaugh & Maholik, 1964)

Crumbaugh and Maholik (1964) developed this test to evoke responses believed related to the degree to which the individual experienced purpose in

life. The scaling dimensions within this measure are somewhat unorthodox in that the anchor points for each item are unique to that item. Respondents are required to denote the extent to which their views of life correspond to points on the seven-point scale for each item. Harlow *et al.* (1987) has referred to the format of the test as "awkward and bulky" and suggests that it assesses "existential frustration". The PIL Test has been widely used with a diverse range of populations such as people with alcohol problems (March *et al.* 2003; Waisberg & Porter, 1994), victims of political persecution (Czaja, 2001) and with shoplifters (McShane *et al.* 1991). Robak and Griffin (2000) used the test to examine relationships between life purpose, happiness and grief. It has been used to explore links with psychopathology in general (Moomal, 1999); to understand the impact on parents of their child's death during military service (Florian, 1989) and as a means of understanding contributors to death anxiety (Quinn & Reznikoff, 1985).

Table 3.2

Illustrative Items from Purpose in Life Test

I am usually	Completely bored	Exuberant, enthusiastic
Life to me seems	Completely routine	Always exciting
In life I have	No goals or aims at all	Very clear goals and aims
I have discovered	No mission or purpose in life	Clear cut goals and a satisfying life purpose

There are very few studies of the use of the PIL Test with people who have had cancer. Henrion (1983) administered this measure to a heterogeneous sample of ten patients with cancer. Although there are significant limitations regarding the conclusions that can be drawn from the application of this measure to such a small sample, she concluded that the people with cancer in her sample had 'lower' purpose and meaning in life than the patients in Crumbaugh and Maholik's research (Crumbaugh & Maholick, 1964). She reported that this was greater though than the patients with diagnoses of schizophrenia. Schnoll *et al.* (2002) used this test as part of their study to examine demographic, clinical and psychosocial correlates of adjustment to cancer. It has been shown to have adequate internal reliability (alpha =0.86, Harlow *et al.* 1987; alpha =0.90, Schnoll *et al.* 2002).

Reker and Cousins (1979) have presented data that support the factorial validity of this measure. Reker and Cousins (1979) combined responses on the PIL Test and Seeking of Noetic Goals (a related test developed by Crumbaugh) and subjected these data to principal components analysis. This identified component dimensions that accounted for 61% of the variance and were labelled 'Purpose in Life', 'Goal Seeking', 'Goal Achievement'. 'Contentedness with Life', 'Existential Vacuum', 'Search for Adventure',

'Futuristic Aspirations', 'Internal-External Locus of Control', 'Self-fulfilment' and 'Life View'. Six of these dimensions related to items on the PIL test. Reker and Peacock (1981) developed the Life Attitude Profile from this analysis.

Harlow *et al.* (1986) produced the revised Purpose in Life Test (PIL-R) by rephrasing the original items "for ease of presentation". They have reported data that support the construct validity of the PIL-R (Harlow *et al.* 1987). They reported a large general factor plus four primary factors. These were labelled as 'Lack of Purpose in Life', 'Positive Sense of Purpose', 'Motivation for Meaning' and 'Existential Confusion'. However, Dufton and Perlman (1986) examined the factor structure and suggested a two-component solution assessing 'life purpose' and 'life satisfaction' and that these two constructs are confounded. The conceptual coherence of this measure has also been questioned byDyck (1987) on the basis of its statistically significant relationships with a range of measures of depression.

3.2.2 Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing Scale (FACIT-Sp) (Peterman *et al.* 2002)

This measure is based on the parent system of measures called 'Functional Assessment of Chronic Illness Therapy' (formerly Functional Assessment of Cancer Therapy). These consist of a series of quality of life measures that have been tailored to specific tumour types and issues or problems that commonly present among people with cancer (Cella *et al.* 1993). The impact of cancer on spiritual variables led to the development of a scale to assess spiritual wellbeing. It is a 12-item measure for the assessment of spiritual wellbeing and comprises two subscales. The subscales are designed to assess 'sense of meaning' and 'role of faith in illness'. In keeping with the other

measures that have been produced by this research team, respondents choose from responses on a five point Likert scale that comprises responses to reflect the extent to which items are reflective of experiences in the seven days prior to interview. These are labelled 'Not at all', 'A little bit', 'Somewhat', 'Quite a bit', 'Very much'.

The emphasis on global meaning within this scale is apparent from inspecting the items that comprise the 'sense of meaning' subscale. This includes the items 'I have a reason for living' and 'I feel a sense of purpose in my life'. Cancer is not specifically linked with the concepts that are reflected within the individual items, further supporting the global meaning emphasis of this measure.

Table 3.3

Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing Scale

Meaning Subscale
I feel peaceful
I have a reason for living
My life has been productive
I have trouble feeling peace of mind
I feel a sense of purpose in my life
I am able to reach down deep into myself for comfort
I feel a sense of harmony within myself
My life lacks meaning and purpose
Faith Subscale
I find comfort in my faith or spiritual beliefs
I find strength in my faith or spiritual beliefs
My illness has strengthened by faith or spiritual beliefs
I know that whatever happens with my illness, things will be okay

Peterman *et al.* (2002) carried out a principal components analysis on the 12-item measure. This resulted in a three-component solution, but as the third component comprised only two items and given that it was these items that were the only ones with negative wording, it was decided to retain and examine the two component solution. This research study also examined the validity and reliability of the FACIT-Sp. One study examined the relationship of the measure with quality of life, affect and demographic status. A second looked at relationships between religion, spirituality and global meaning. The FACIT-Sp has been shown to have good internal consistency and reliability. Alpha for the total and subscale scores has been reported to vary between 0.81 and 0.88. The FACIT-Sp Faith subscale correlates moderately to highly (r=0.39-0.75) significantly with index measures, demonstrating a highly acceptable level of convergent validity for this subscale. The FACIT-Sp Faith subscale correlated (rho = 0.38) with the LAP Coherence subscale and (rho = 0.75) with the Spiritual Beliefs Inventory.

The relationship of scores to assessments of organisational religious activity and non organisational religious activity have been reported as significant and are in the predicted direction. None of the correlations with the Meaning/Peace Subscale met criteria for shared variability (Peterman *et al.* 2002). The total FACIT-Sp score also correlated moderately (rho = 0.31-0.48) with the other measures. Discriminant validity has been demonstrated in that higher scores on the FACIT-Sp have been shown to be associated with lower scores on the Profile of Mood States Depression Subscale score. This was examined by Analysis of Variance of the FACIT-Sp scores of three groups of

patients, divided on the basis of their POMS-Depression scores ($p<0.001$), in keeping with the prediction that people with a greater sense of spiritual wellbeing will have lower depression (Peterman, personal communication). Cotton *et al.* (1999) reported significant correlations with quality of life and psychological adjustment but this relationship with quality of life was less apparent when relationships were examined using multivariate statistics that controlled for the effect of demographics and adjustment styles. This contrasts with the findings of Brady *et al.* (1999) who reported a more significant contributory influence of spiritual wellbeing to quality of life.

Clinically this scale has a number of important strengths. These relate to the fact that the constructs of religiosity and spirituality are not confounded. This makes the measure particularly suitable for the assessment of patients who believe themselves to be more spiritual than specifically religious. The lack of reference to specific religious groupings makes the scale more generally useful than measures that assess specific denominational beliefs. It has been suggested that the FACIT-Sp Meaning and Peace Subscale is a proxy measure of emotional wellbeing (Koenig *et al.* 2001). However, Peterman *et al.* (2002) suggest the need to further examine the construct validity of the Meaning/Peace subscale before making definitive statements on this issue. The production of a reliable and valid measure for spiritual wellbeing is a vital step forward to begin to examine how this concept relates to global meaning constructs and to elements of psychopathology and adjustment. McClain *et al.* (2003) used the scale to examine the effect of spiritual wellbeing on end of life despair among people with incurable cancer.

3.2.3 Life Orientation Test (LOT) (Scheier & Carver, 1985)

This scale consists of twelve items, only eight of which contribute to the total score for measuring dispositional optimism. Four of these are positively phrased and the remainder are negatively phrased. Respondents are invited to provide a response from a five point Likert scale reflecting level of agreement with the constituent items ('I agree a lot', 'I agree a little', 'I neither agree or disagree', 'I disagree a little' and 'I disagree a lot'). The Life Orientation Test - Revised was developed by Scheier *et al.* (1994). It is briefer than the original and contains ten items (only six contribute to the overall measure as four are 'filler items'). The LOT-R has been shown to have good internal consistency (alpha between 0.70 and 0.80, Carver & Scheier, 2002).

Table 3.4

Illustrative Items from the Life Orientation Test

In uncertain times, I usually expect the best
I always look on the bright side
I'm always optimistic about my future
I hardly ever expect things to go my way
Things never work out the way I want them to
I rarely count on good things happening to me

Test retest reliability for the original measure has been shown to be good (0.72 over a 13 week period). Changes on the score have been reported when it was given to people who had had a stroke six months apart (Schulz *et al.* 1988). Factor analyses have confirmed that the scale is unidimensional. Evidence for convergent and discriminative validity has also been reported (Scheier & Carver, 1985; Carver & Scheier, 2002). It has been suggested,

however, that the LOT is a proxy measure of negative affectivity and neuroticism (Smith *et al.* 1989).

3.2.4 Life Attitude Profile - Revised (Reker, 1992)

The original Life Attitude Profile was developed by Reker and Peacock (1981). This consisted of 56 items and was developed using items from existing scales - the Purpose in Life Test (referred to earlier), Seeking of Noetic Goals Test, Personal Orientation Inventory (Shostrom, 1962) and the Death Perspective Scale (Lowe *et al.* 1979). The Life Attitude Profile -Revised (LAP-R) is a 48 item self report measure of discovered meaning, purpose in life and the motivation to find meaning and purpose in life. Reker (1992) states that "it is the product of a number of refinements based on a combination of theoretical, rational and factor analytic procedures". (p.13). Items are rated on a seven point Likert scale of agreement ranging from 'strongly agree' to 'strongly disagree'. It takes approximately 15 minutes to complete and has been shown to have high internal consistency and test-retest reliability. The LAP-R has been hypothesised to have six subscales named as 'Purpose, Coherence, Choice/Responsibleness, Death Acceptance, Existential Vacuum and Goal Seeking'. Reker has suggested that composite scores can be computed for 'Personal Meaning Index' and 'Existential Transcendence' scales. These scales have been validated by principal components analyses on a large sample (n=750). The components that were identified accounted for 47% of the variance. This scale has been used in studies to examine changing attitudes with increasing age (Reker *et al.* 1987, Cappeliez & O'Rourke, 2002). It has also been applied with people experiencing physical illness. Park (2003) used it in his study of purpose in life and its relationship to adjustment to chronic pain and Konstam *et al.* (2003) have used this scale to understand the

experiences of people in caregiver roles for relatives with Parkinson's Disease. Like the Purpose in Life Test it has been used within studies with participants reflecting a diverse range of experiences from understanding boredom and violence among adolescents (Guiliano, 2002) and adjustment of mothers to the death of their only child (Talbot, 1996; Talbot, 1997). The Personal Meaning Index has been used by Johnson-Vickberg and her colleagues (Johnson-Vickberg *et al.* 2001) in her studies referred to earlier on global meaning and adjustment to cancer.

Table 3.5

Illustrative Items from the Life Attitude Profile - Revised

The meaning of life is evident in the world around us
I try new activities or areas of interest and then these soon lose their attractiveness
It is possible for me to live my life in terms of what I want to do
I have a framework that allows me to understand or make sense of my life
A new challenge in my life would appeal to me now
I accept personal responsibility for the choices I have made in my life

The LAP-R has acceptable reliability with alpha coefficients reported between 0.77 and 0.91 (Reker, 1992) and test retest reliability figures over a four to six week interval that are of a similar magnitude (0.77-0.90) (Reker, 1992). Profiles of this measure have been shown to support the LAP-R as a valid measure of the construct that it purports to assess. Scores have been demonstrated to be higher for older than younger adults in keeping with the prediction that sense of meaning and purpose is greater for older people. The personal meaning scale demonstrates significant correlations with other

measures of global meaning such as the Sense of Coherence Scale (r=0.50) and the Purpose in Life Test (r=0.82). This measure has good normative data from non-clinical samples.

3.2.5 Sources of Meaning Profile - Revised (SOMP-R) (Reker, 1996)

This is a 17-item measure that measures the sources that provide an individual with a sense of meaning and purpose in life. Higher scores indicate that the respondent has a large number of meaningful sources within their life. It is scored according to a seven point Likert type scale that is anchored with "not at all meaningful" to "extremely meaningful". In addition to being able to compute a total score, it is also possible to calculate what is referred to as a 'breadth' score - the number of items scored by respondents greater than or equal to five (i.e., more than moderately meaningful up to extremely meaningful). Reker (1996) reported the results of a principal components analysis that identified four factors, labelled as 'Self Transcendence', 'Collectivism', 'Individualism' and 'Self Preoccupation'. Studies that have used this measure report internal consistency to be good, relating to alpha coefficients of between 0.71 and 0.80. Test retest reliability over a three month period has been reported as 0.70. The internal consistency of the factor scores has been reported to be weak. In an attempt to address this, Reker has suggested that the subscales be combined to form the higher order scales of 'Transcendence' and ' Actualising'. The SOMP-R correlates significantly ($r=0.42$, $p<0.005$) with the Personal Meaning Index of the Life Attitude Profile referred to above, attesting to the concurrent validity of the measure.

Table 3.6

Illustrative Items from the Sources of Meaning Profile

Participation in leisure activities
Meeting basic, everyday needs
Engaging in personal relationships with family and friends
Being of service to others
Acquiring material possessions to enjoy the good life
Leaving a legacy for the next generation

This measure has been mostly used to examine how scoring profiles change with increasing age (Prager, 1998; Prager *et al.* 1997). If studies of the psychometric properties of this scale in a population of people with cancer were to suggest it as a robust measure, then it could be used to examine the ways in which sources of meaning relate to the experiences of people with cancer. Potential links with distress and wellbeing could be explored alongside opportunities to develop interventions that would enable patients to experience sources of meaning that were hitherto underdeveloped.

3.2.6 Sense of Coherence Scale (Antonovsky, 1993)

This is a 29 item semantic differential scale that is based on the eponymous theoretical construct. The Items are each presented with a seven point Likert scale with anchor labels that are different for each item. Item content reflects Antonovsky's conceptualisation of sense of coherence. This has been defined principally as:

*"..a **global** (emphasis added) orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that*

stimuli derived from one's internal and external environments in the course of living are structured, predictable and explicable" (Antonovsky, 1993, p.725)

This theory was used to generate item content during the initial stages of scale development. This scale has been used in a wide variety of studies where internal consistency has been reported to be high (Antonovsky, 1993) with alpha scores for the 29 item version being cited in published studies between 0.86 and 0.95. Test retest reliability has been reported to be in the order of 0.52 and 0.80. It has been suggested to have "one clear dominant factor" (Antonovsky, 1993). Antonovsky (1993) report data from six studies each of which report the results of principal components analyses. All of these suggest that the Sense of Coherence Scale has one global factor. A short form of this measure has been developed, consisting of 13 items. Sense of coherence has been examined with regard to treatment decision making preferences in a group of people with cancer (Ramfelt *et al.* 2000) and in relation to its links with coping and spiritual thinking in a group of patients with brain cancer (Strang & Strang, 2001).

Table 3.7

Illustrative Items from the Sense of Coherence Scale

Items are outlined and are followed by details of the anchoring labels that are used for the item outlined.
When you talk to people, do you have the feeling that they don't understand you?
Never have the feeling ... Always have this feeling
1 2 3 4 5 6 7
In the past, when you had to do something which depended upon cooperation with others, did you have the feeling that it
Surely wouldn't get done ... Surely would get done
1 2 3 4 5 6 7
Most of the things that you do in the future will probably be
Completely fascinating ... Deadly boring
1 2 3 4 5 6 7

3.2.7 Meaning in Suffering Test (MIST) (Starck, 1983)

Starck (1983) described the purpose of this test as to ascertain the respondents' perception of the extent to which they found meaning in suffering experiences. The measure consists of two parts. The first is a self-report measure consisting of 20 items. Responses on MIST Part 1 are scored using a seven point Likert scale that is labelled as 'Never', 'Rarely', 'Occasionally', Sometimes, Often, Very Often and Constantly'. The second part of MIST invites participants to verbalise their suffering experiences, coping mechanisms and to provide information that is relevant on the basis of other people that are known to the respondent. This measure has not been

widely used and it has not been possible to locate any data on its use with clinical populations.

Table 3.8

Illustrative Items from the Meaning in Suffering Test

Part 1
I believe suffering causes a person to find new and more worthwhile life goals
I believe everyone has a purpose in life; a reason for being on earth
I believe my suffering is part of a grand design even though I may not always understand it
I believe that people are not given more suffering than they can bear
I believe suffering occurs if a person is unlucky and fate has been unkind
Part 2
On a scale from 1-10 how would you rate your suffering experiences?
What do you think suffering teaches if anything? (Name 3 if possible)
What, if anything helps you get through the suffering? (Name at least 3 things)
What "good" or positive aspects resulted from your suffering (Name 3 if possible)
What "bad" or negative aspects resulted from your suffering (Name 3 if possible)

3.2.8 World Assumptions Scale (Janoff-Bulman, 1989)

This scale was developed from a theory of the way in which exposure to traumatic events results in changes to the beliefs and assumptions held by those involved. The main component of this theory relates to the need for individuals to assimilate their trauma within existing belief structures or, if this is not possible, to accommodate the event within a revised set of beliefs and assumptions. The model proposed that there are eight cognitive themes underpinning the beliefs that are most often challenged by a personal trauma

and it was these themes that informed the initial development of the item pool. The clearest, most straightforward and most unambiguous items for each assumption were combined. Two hundred and fifty four completed an initial 64 item version of the questionnaire. Analysis of alpha coefficients was used as the basis for excluding items. This resulted in a 32 item questionnaire that consisted of eight subscales each consisting of four items. Respondents were required to indicate the extent to which they agreed with each item using an eight point Likert scale that ranged from "disagree completely" to "agree completely".

Table 3.9

Illustrative Items from the World Assumptions Scale

Misfortune is least likely to strike worthy, decent people
Human nature is basically good
Life is too full of uncertainties to be determined by chance
People are basically kind and helpful
The world is a good place
I have reason to be ashamed of my personal character

Factor analysis was then carried out on a version of the scale. Janoff-Bulman (1989) does not report detailed quantitative data on the resultant structure of the measure, though outlines that the emergent structure was almost completely identical to that proposed by her theory and therefore the initial allocation of items to the subscales. The seven subscales that were identified were labelled as Benevolence of the World, Benevolence of People, Justice, Controllability, Randomness, Self Worth, Self Controllability and Luck. These were subsequently combined to form what appear to be three higher order subscales named 'Benevolence of the World', 'Meaningfulness of the World'

and 'Self Worth'. This scale has been used mostly in the context of understanding psychological reactions to adjustment following traumatic events such as sexual abuse (Owens *et al.* 2001) or the murder of a child (Wickie & Marwit, 2001). There are also reports of it being used to understand the contribution of global beliefs on self reported drug and sex related risk behaviours (Avants *et al.* 2003).

The preceding section has examined measures of global meaning. The following sections will consider measures that focus on situational meaning.

3.2.9 Illness Cognition Questionnaire (Evers *et al.* 2001)

This is an 18 item measure that assesses the extent of respondent agreement with a list of statements about the personal experiences of physical illness. Agreement is divided into four points along a Likert scale, 'Not At All', 'Somewhat', 'To a Large Extent' and 'Completely'. There are three subscales, namely 'Helplessness', 'Acceptance' and 'Perceived Benefits'. This measure was developed using exploratory factor analysis with a large sample of patients with Rheumatoid Arthritis (n=263), the results of which were then used in a confirmatory factor analysis with a sample of patients with Multiple Sclerosis (n=167). Subscales have been demonstrated to have very good internal consistency (alpha between 0.84 and 0.91) and adequate test-retest reliability (r = 0.68-0.79). There is a need for further research on construct validity in order that links with self efficacy and locus of control can be examined.

Table 3.10

Illustrative Items from the Illness Cognitions Questionnaire

My illness makes me feel useless at times
My illness frequently makes me feel helpless
I have learned to live with my illness
I can accept my illness well
Dealing with my illness has made me a stronger person
My illness has helped me realise what's important in life

Acceptance has been shown to be related to better psychological health, less neuroticism and more optimism. Concurrent validity has been shown when subscale scores are compared with scores on criterion measures. Partial correlations were computed to take account of the contribution of neuroticism to relationships. Patients with higher scores on the Helplessness subscale experienced more pronounced levels of disease activity (r=0.47), functional disability (r=0.54) and physical complaints(r=0.38), increased negative mood (r=0.40), decreased positive mood (r=-0.33) and increased daily disease impact (r=0.56). This subscale also demonstrated expected relationship links with personality dimensions such as neuroticism and optimism, further strengthening these data on concurrent validity.

Predictive validity was established by examining the links between responses on the measure and subsequent changes in physical and psychological health over the course of 12 months. Helplessness related to functional disability (r=0.23). Acceptance was linked with improvements in physical and psychological health, specifically with less disease activity (r=-0.20) and physical complaints (r=-0.20). Part of the appeal of this measure is the potential applicability across a range of chronic diseases and the inclusion of

what the authors refer to as 'maladaptive and adaptive' cognitions. The thorough and comprehensive way in which the authors have examined the validity of the measure is a strong factor that commends this scale.

3.2.10 Life Evaluation Questionnaire (Salmon *et al.* 1996)

Salmon *et al.* (1996) developed this measure in order to address a perceived gap in the coverage of various cancer related quality of life measures. They specifically suggest the need for the development of a measure that covered issues of particular relevance to people with a 'fatal illness'. They developed this measure on the basis of a principal components analysis on the responses of a heterogeneous sample of people with cancer (n=200). This suggested five components that accounted for 37% of the variance. These were labelled 'Freedom'. 'Appreciation of Life', 'Contentment', 'Resentment' and 'Social Integration'.

Table 3.11

Illustrative Items from the Life Evaluation Questionnaire

I find it easy to relax - I find it impossible to relax
My illness has not upset important plans - My illness has upset important plans
I think that there is something in use that lives on after we die - There is nothing that lives on after we die
I get depressed often - I never get depressed
My visits to the doctor or hospital are badly disrupting my life-My life is not disrupted by my visits to the doctor or hospital

There are 61 items, each with a seven point semantic differential type scale with two endpoints each labelled with wording to reflect the content being

assessed for the item. Although this measure was developed in a sample of patients with incurable cancers, the items are phrased to cover illness in generic terms. Each subscale has been shown to have good internal consistency (alphas between 0.70 and 0.85) and test-retest reliability (0.77-0.91). Although containing specific elements of cancer specific situational meaning (i.e., 'I appreciate things more than I did') it also contains coverage of constructs that have greater connection to the effects of symptoms on the lives of patients. This measure has not been used in any published studies.

3.2.11 Constructed Meaning Scale (Fife, 1995)

This scale provides a measure of meanings associated with adaptation to life threatening illness. It was developed on the basis of interviews that were conducted with people who had cancer and that were aimed at enabling them to provide a perspective on the meaning of cancer for their lives (Fife, 1994). Fife (1995) describes the scale as having eight items. A subsequent version of the scale (sent by Dr Fife to the author upon request) consisted of 14 items. Items are rated according to the level of agreement using a 4-point Likert scale that varies from 'Strongly Agree' to 'Strongly Disagree'. It has been shown to have good internal consistency with alpha scores reported of 0.81 (Fife, 1995) and 0.85 (Fife, personal communication). The range of corrected item-total correlations has been reported to be from 0.54-0.73 (Fife, 1995) and 0.35 to 0.74 (Fife, personal communication). Fife (1995) examined the psychometric properties of this scale in a sample (n=422) of people with cancer. Principal components analysis resulted in the identification of two factors, accounting for a total of 53.7% of the variance. The second factor consisted of two items, each loading significantly on the first and second factor. A one component solution was proposed as a result of this observation.

Fife (personal communication) reported that factor analysis of responses in a sample of patients with HIV infection (n=130) and cancer (n=76) to the 14 item version of the scale also identified one factor that accounted for 70.8% of the variance.

Table 3.12

Illustrative Items from the Constructed Meaning Scale

I feel my illness is something I will never recover from
I often feel I am an outsider because of my illness
I feel victimised by my illness
The uncertainty of my illness is causing me great difficulty
I feel that my illness has interfered with achieving the most important goals I have set for myself

Fife reported that the scale scores were in the expected directions when total scores of people with newly diagnosed cancer, a first recurrence or metastatic cancer were compared. Fife also found that, in keeping with expected relationships between illness specific meaning and mood, statistically significant correlations ($r = 0.41$-0.5) between scores on the Profile of Mood States and this measure were observed. Regression analysis of the contribution of perceived social support confirmed that perceptions of social support from the perspective of friends, professionals and family all contributed to variance in illness related meaning. The validity of this measure was further supported by the observations that scores were related to coping responses measured by the Ways of Coping Checklist, revised by Vitaliano (1985). The use of denial ($F=59.42$, $p< 0.01$), avoidance ($F=40.81$, $p<0.01$) and positive focusing ($F=10.03$, $p< 0.01$) were predictive in a

regression analysis of the nature of meaning that individual patients developed about their illness (Fife, 1995). Fife also demonstrated that scores on this measure contributed to the variance in a number of other conceptually related constructs such as control and quality of life (Fife, 1995). It is highly correlated with self-esteem, personal control, body image and emotional responses to illness (Fife, personal communication). This scale has been used in a study examining a range of contributors to adjustment following divorce (Bevvino, 2000) and in a study that sought to understand the links between coping and meaning of illness among a group of people with HIV infection (Fostner, 1997). It has not been used in any work with people who have cancer, other than the initial sample of patients reported in the work of Fife (1995).

3.2.12 Other Meaning Assessment Methods

Some researchers have developed other methods within their research to access meaning. Thompson and Janigian (1988) measured meaningfulness of life using an unnamed 13-item scale consisting of items such as 'I feel that my life is meaningful right now' and 'It seems very unfair that I got cancer'. It has been reported to have adequate internal consistency (Thompson & Pitts, 1993). Schussler (1992) assessed the individual meanings ascribed to illness experience by using "An extensive biographical case history and evaluation of the illness concepts based on biographical interview" (p. 428). Barkwell (1991) assessed the meanings ascribed to pain by patients with advanced cancer using Face to Face Interview. Unfortunately neither Schussler nor Barkwell provide any further detail on the constituent components of their assessment method. DeVogler and Ebersole (1985) invited participants to write essays about what gave participants meaning in their lives and then rated content

according to how 'deep' the meaning in their lives was. Thompson (1985) measured the extent to which patients had found positive meaning by inviting respondents to write their answers to a list of questions phrased to elicit information on the proposed ways in which patients had been 'focusing on the positive'. Thompson stated that 'These six items were summed to produce an overall measure of focusing on the positive'. No further information is provided on what these questions are, how their content was derived or the rationale and procedure for summing the items to produce an overall score.

3.3 Discussion and Conclusions

The preceding sections have considered a range of commonly available methods to assess components of global and situational meaning. Although there is a large degree of variation in the psychometric performance of measures and whether they have been developed or applied in cancer settings, some clearly stand out as being more appropriate to use. This Chapter will conclude with some statements on the current state of measurement of meaning in psychosocial oncology.

The Life Attitude Profile-Revised has good psychometric properties and there are data demonstrating productive application of a subscale (the Personal Meaning Index) within cancer settings. Researchers will want to consider this measure before others when examining global meaning among people with cancer. The FACIT-Sp has an excellent psychometric profile and is clearly the measure of choice for clinical and research assessments of spiritual dimensions of global meaning.

The Illness Cognition Questionnaire is a short scale that has impressive psychometric data and a component structure that has been shown in both exploratory and confirmatory analyses. As a generic assessment of situational meaning it is clearly the gold standard for examining the impact of physical illness on individual experiences. Although these measures have been singled out, further research is required to better understand their performance among people with cancer and to make progress in developing theoretical understanding of how meaning relates to the lived experience of people with cancer.

Although the World Assumptions Scale has been empirically derived, psychometric data are not easy to obtain and there have been no attempts to use this measure with people who have had cancer. There are good psychometric data on the Sense of Coherence Scale but it less relevant for use in work on global meaning in general, but very appropriate when specific elements of Antonovsky's theory are being examined. Although possessing a high degree of face validity, the length of the Life Evaluation Questionnaire and lack of further data on people with cancer, suggests it should be subject to further research before more widespread application can be recommended. The links between meaning and trait factors such as neuroticism suggests that future work to understand the performance of all of these measures should be conducted in a manner that allows for the influence of neuroticism or negative affectivity. The work of Evers *et al.* (2001) on the Illness Cognition Questionnaire provides an example of how this can be achieved.

There are some measures that, although in need of considerable development with regard to their psychometric performance, could significantly extend

knowledge of the phenomenology of meaning in cancer and how this might relate to other key constructs within psychosocial oncology. One such measure is the Sources of Meaning Profile. In addition to the need for data to better understand how this measure performs when administered to people with cancer, descriptive data might assist clinicians to identify areas for clinical initiatives to facilitate access to meaningful activity and suggest mechanisms by which therapists might wish to promote wellbeing. Subject to appropriate caveats regarding psychometric performance, this measure might be of use to clinicians wishing to explore sources of meaning as part of their assessment, case conceptualisation and psychosocial interventions.

As more people live longer with cancer, there is a greater need to understand the conceptual links between meaning and the psychological experience of living with cancer. There is a need for focus on issues such as the potential protective effects of particular constellations of global meaning constructs that existed prior to a cancer diagnosis; the extent to which psychotherapeutic interventions impact upon global and/situational meaning and how such changes might relate to changes in general wellbeing or quality of life. The emergence of therapeutic groups that specifically target meaning suggests that this work is already beginning to take place and that this too will generate a need for clarity on the measures with better psychometric performance. Scale development work in this area has started to differentiate the potential importance of understanding the relationships between positive and negatively valenced meanings and this too will be an important distinction as psychosocial oncology, and psychology in general, begins to explore the practical implications of emphasising positive elements of adjustment and wellbeing (Huppert & Whittington, 2003; Maddix, 2002).

Available measures that have the most robust psychometric properties are largely related to global meaning. It is these that have been applied to the study of meaning and cancer. The Illness Cognition Questionnaire and the Constructed Meaning Scale are available for the assessment of generic situational meaning. There are not measures that specifically target situational meanings that are specific to cancer. This significantly hampers work to better understand the interpretations, processes and outcomes that have been suggested to be so important to appreciating psychological adjustment to cancer. There is also a need for a cancer specific assessment of situational meaning in order that the relationship with global meaning dimensions can be researched and better understood.

SECTION TWO METHOD AND RESULTS

Having established that (a) the construct of meaning has been proposed as a mediating, moderating and outcome variable regarding psychosocial adjustment to physical illness, (b) that it is possible to delineate two levels of meaning (global and situational) and that (c) there are no specific measures available to examine situational meaning in cancer, this section will outline empirical work undertaken to develop such a measure.

Chapter 4 Developing a Pool of Items for the Core Cancer Meanings Measure

4.1 Introduction

This Chapter addresses the first phase in the development of a measure of situational meaning - the derivation of the item pool. The next Chapter will outline the components of a peer review process and work undertaken during the initial field testing of the measure. The emphasis on situational meaning and definition of what is meant by this term will be outlined and the approach adopted for the development of this measure will then be addressed.

4.1.1. Approach taken to Scale Development

Dawis (1987) has suggested that scale development must first include efforts to define the variable to be measured and that this should include distinctions about what the variable is, as well as what it is not (this will be covered in the next section at 4.1.2). He suggests a range of factors that need to be considered. These are outlined in Table 4.1. The remaining sections in this Chapter will outline how the development of a measure of cancer related situational meaning was progressed using this framework. The approach that was adopted involved the successive implementation of phased stages. This started with the derivation of an item pool with transcript data from a group of patient interviews, was followed by peer review to refine scale content and format; patient field testing with a further sample to analyse acceptability of a preliminary form and then application of the new scale to another new patient sample.

This will be referred to as 'core' situational meaning and the measure will be known as the Core Cancer Meanings Measure (CCMM).

4.1.2 Definition of Core Cancer Meanings at the Situational Level

As a preliminary step toward the development of a new measure of situational meaning, the definition of core cancer meanings at the situational level will be outlined and the initial steps taken to develop a measure of this will then be described. Cancer related meaning will be defined for the purpose of scale development as relating to the thoughts and beliefs reported by patients who have had the experience of cancer. This does not necessarily relate to situating this experience within a total life pattern or belief system or to thoughts and interpretations that relate to coping attempts or other psychosocial dimensions of illness experience. Beliefs that imply reference to global meaning structures such as 'My life is in perspective because of cancer' are regarded as being situationally specific in that, although relating to an overall global meaning concept (degree to which life has perspective), this is making specific reference to this being as a result of cancer. If, on the other hand, the belief had been 'My life has no perspective' then this would be viewed as a reflection of global meaning. The use of the term 'core' is related to the fact that the work that will be described here is not aimed at encompassing beliefs that are specific to the site of their tumour, nature of their treatment or other idiosyncratic elements of their life situation. The emphasis is instead on having cancer in general terms.

Table 4.1

Dawis (1987) Suggestions for Factors to Inform Initial Stages of Scale Design

Overall Design
Well articulated definition of variable (related to theory)
Distinctions of variable
Dependencies on more basic terms
Relationship with other variables
How is the variable best represented
Who will the respondents be
Conditions under which measure will be administered
Scale Content
Conduct open ended interviews with respondents from target population
Define desired level of scale homogeneity
Scale Format
Choose simplest format
Decisions on item stems
Consider response options - measurement dimension
- response format
Scale Development
Collect data using preliminary form
Analyse data for a "more final" form
Check ease of following instructions, length of time to complete and appropriateness of items

4.2 Method

In view of the importance of recruiting patients that were currently attending for ongoing medical review in connection with recent cancer diagnosis or

treatment, it was decided to meet with a range of Medical Consultants at the Beatson Oncology Centre, Glasgow to discuss a planned study to develop this measure. These meetings focused upon discussion of the need for a measure to assess situational meaning and the proposed method for the recruitment and participation of patients. Twenty-one Consultants in Clinical or Medical Oncology agreed to participate in the study. They were invited to complete declarations of agreement (see Appendix 1) indicating that they were happy for patients under their care to take part, if they provided their written consent in accordance with the protocol that had been submitted and approved by the West Ethics Committee of West Glasgow Hospitals University NHS Trust (see Appendix 2).

The Likert method of developing 'subject-centred scales' (Dawis, 1987) was chosen in accordance with the principles of a deductive method of scale development. The first step is that items are written to represent the domain to be assessed by the measure. Dawis (1987) suggestion of conducting open-ended interviews with representative individuals from the target respondent population was adopted to develop a pool of items that represented the cancer related meanings and interpretations that would become the content of the new measure.

4.2.1 Sample

Sampling was undertaken with the aim of recruiting a heterogeneous sample of patients with regard to tumour site, the presence or absence of locoregional or metastatic spread and the number of previous episodes of cancer. A heterogeneous sample was recruited (n=56) in order to ensure that interview content could focus on core aspects of cancer meaning irrespective

of individual differences in cancer site or treatment regime. It was considered important to include patients with metastatic disease in order that data on meaning experienced by these patients could be included in the development of items for inclusion in the first versions of the questionnaire. Although the aim of the study was to focus on meaning that would be core to all tumours and prognoses this could only be achieved by including some participants with cancer that had a poor prognosis. When recruitment had identified a number of patients with certain tumour types further sampling was targeted at the recruitment of patients with tumour types, or experiences that had not been included in the sample at that point in the study. The characteristics of the tumour site descriptions from this sample are outlined at Table 4.2 Of these 56 patients, 16 had metastatic disease and the remainder had localised or locoregional disease. These disease status characteristics were provided by patients themselves and it is therefore possible that there were more patients with metastatic disease than it would appear on the basis of this description which is classified on the basis of self report (as opposed to casenote review for pathological diagnosis).

Table 4.2

Primary Cancer Site of the Patients that Participated in Interviews to Generate the Pool of Items

Site of Cancer	% of Sample (N)
Lung	6
Bladder	1
Ovary	4
Colon	13
Unknown	1
Osteosarcoma	1
Brain	3
Prostate	3
Breast	17
Oesophagus	1
Testicle	2
Cervical	1
Leukaemia	3

The case notes of patients scheduled to attend randomly chosen clinics of the participating Consultants were reviewed to identify potentially suitable patients. Patients were identified as potentially suitable if they had received a diagnosis of cancer within the past 12 months (first diagnosis or a recurrence). In addition to having a confirmed diagnosis of cancer, patients had to be aged 18 years or over, have no evidence of dementia or an acute confusional state or of rapidly deteriorating physical health status.

Sampling to redundancy (where recruitment continues until saturation in theme content appears) (Barker *et al.* 2002) was the approach used to recruit participants for the first phase to develop questionnaire items. Patients are interviewed until identical themes begin to emerge from the transcribed interviews (Barbour, 1999). The choice of a heterogeneous sample for the purpose of scale development is the preferred method for studies focused on initial scale development (Streiner & Norman, 1995) and is the one that has been adopted by those involved with other well known self-report scales in oncology such as the Mental Adjustment to Cancer Scale (Watson *et al.* 1988).

An example of how this operated in practice was that when sufficient numbers of women with breast cancer had been recruited (determined on the basis of repeated themes occurring in these interviews) efforts were focused upon identifying people with tumours at other anatomical sites (e.g., lung) and/or with differing illness experiences (e.g., delayed diagnosis) until similar themes were identified or new themes emerged.

4.2.2 Procedure

Patients were identified by the researcher from the clinic lists of Consultants in Clinical and Medical Oncology, the day chemotherapy ward and the lists of patients scheduled to attend for radiotherapy at the Beatson Oncology Centre. Patients were invited to consider becoming involved in the study by the researcher or a member of the clinical team involved in their care. Patients expressing an interest following initial approach were given an information sheet that outlined the background to the study (see Appendix 3). When patients had been given at least 24 hours to consider participation in the research study, they were contacted to provide them with the opportunity to ask questions and to confirm whether or not they wished to participate. Patients who wished to participate were invited to attend an appointment at the Beatson Oncology Centre with the researcher.

At this appointment, patients were provided with a detailed explanation of the procedural elements of the study and provided their consent both to participate and for the interview to be audio-taped for later analysis (see Appendices 4 and 5). Following the completion of this interview, audiotapes were stored securely within a locked office at the Department of Psychological Medicine, University of Glasgow. The staff of an independent transcription company collected tapes, transcribed these and returned these to the University Department. Secure arrangements were made for the storage and transportation of the tapes (Appendix 6).

The aim of the interview was to enable patients to provide some background information about their experiences of having cancer and for this information to be used to prompt further questions designed to enable participants to

articulate underlying thoughts, beliefs, meanings or interpretations associated with cancer. This interview was conducted in accordance with a protocol (see Appendix 7). The main components of the interview procedure are outlined in Table 4.3. Salmon *et al.* (1996) have suggested that brief interviews of large numbers can lead to restricted coverage of themes to be included within questionnaires. The protocol was formulated to enable participants to talk openly about their experiences and to facilitate the examination of underlying issues. This protocol embodied a structure where general information on cancer experiences was used to identify salient cues which then became the focus of detailed questioning by the researcher to outline and explore in greater detail the emotional, behavioural and particularly the cognitive aspects of living with cancer.

Table 4.3

Main Components of Interview Procedure used to Generate Material for Pool of Items

(1)	Description of the main problems associated with cancer diagnosis and/or a chronological account of diagnosis of cancer and experience of treatment
(2)	Exploration of the key emotional, behavioural and cognitive dimensions of experience
(3)	Completion of sentence stems to elicit thoughts about cancer experiences
(4)	Follow up questions were incorporated into the protocol to promote elaboration on the cognitions elicited by sentence completion

It was also decided to incorporate a sentence completion component as a further method of generating cognitive content that could then be explored with regard to situational meaning. Initial sentence completions could then be used to explore underlying dimensions of meaning. Elements of the

interviewing style adopted are extracted as examples at Table 4.4 and Table 4.5. These illustrate the way in which questions were chosen to facilitate elaboration of the themes that were reflective of the construct that will form the basis of the measure being developed.

Table 4.4

Example of How the Interview to Generate Pool of Items Encouraged Exploration of Cognitive Dimensions

And how has that made you feel emotionally; the fact that you are very limited?

It can upset me at times. It'll either frustrate me or upset me, and that can make me a bit crotchety or crabbit.

When you're a bit crabbit, what sort of things go through your mind? What do you think about?

Well that's when I'm being negative, negative thoughts start creeping in, and before you know it you're on a downer. And once you start that downward spiral.... It seems unstoppable.

So once you get a couple of negative thoughts, more and more...

That's right, it's a spiral and it continues.

Would you feel able to tell me what a couple of those negative thoughts are in that downward spiral? What do you think to yourself?

Mostly when I look at my family; I'm going to miss them. Later on morphine will take me away from all the pain and it's them who'll be sitting there, it'll be them who have the pain. So they'll be suffering through my illness.

So you find your thoughts focussing a lot on how they'll be?

Family and friends, yes.

Is that something you've talked about with them?

Yes.

Do you ever find that you get any pictures or images in your mind of your family in the future?

Yes, regularly. I try to imagine them ending up how I would like them to be. They're good sorts. Then on the other hand I can look at my family at times and it cheers me up, the fact that they're there, so it's the opposite effect. I find myself re-living my life again. Not that I would want to change things, but I have regrets and I have remorses, and sometimes I think there are unfulfilled ambitions - all the

things I'd have liked to have done that I'll never do. Some days I can accept that, some days I can't. If I was in a negative frame of mind that would just bring me crashing down. And the fact that I'm helpless at times can depress me, if I can't do anything, I'm restricted in what I can do physically - that gets me down because I'm an active person. I was always wanting to be doing something or be something. But as regards death, I've no fear of that. The only thing that causes me most depression is the circumstances of the death and the family I'm leaving.

Are there any times where it's less upsetting, or you maybe think of something that would make it easier for the family, or is it always really difficult to imagine how they'll deal with it?

It's hard to imagine. While you're there you see them as they are; it's when you're not there. I don't mean dead at the time, but maybe in a comatose position. But I can't imagine how they would be. I can imagine that it's never nice, it doesn't offer me any comfort.

So all the images or thoughts about that are not comforting.

No they're not, they're disturbing. But sometimes I can be sitting and I think back to happier times, and it gives me a lift. I can pick out certain instances, dates, occasions.

Have you found that there have been things come to mind in recent weeks that maybe you'd forgotten about?

Very, very much so. In fact, we talked about things on a daily basis that we'd forgotten about for a long time. People and places and occasions. My brother comes in for two hours every day and him and I go back to the past a lot. That cheers me up.

Table 4.5

Example of How Completion of Sentence Stems can be used to Explore Cognitive Dimensions

Okay. What I'd like to do now, I've got a list of sentences which aren't complete, and what I'd like you to do is complete them in your own words. The first question is 'Having cancer means that.....'

You are slapped in the face with the whole of your life, quickly.

'When you get cancer, you....'

Have a lot of organising to do with two small children.

'The main effect of cancer on my life is....'

Complete disorganisation.

'As a person, I am....'

Very strong and very positive.

'When I think about how I feel about myself, I'd say I feel...'

Very focused and now I've got my head round having cancer, very fine with it.

'When I think about other people in relation to my cancer, I think....'

Poor sods. They are the ones that it's worst for, without a doubt.

When you say getting your head round it, what sorts of things did you find you were thinking as you tried to make sense of what's happened?

From the Tuesday night when I went to the Well Woman Clinic and they said they thought there was something, then it was the cancer diagnosis and then it was the sheer practicality of it. Right okay, I have it, how soon are you going to do something about it - are you going to fix it or have I got a timescale to work on here? It was definitely like right, okay, now I've got cancer, so now I have to get a whole lot of things organised, and the only way I can describe it is like having a filing cabinet and having to go through the whole of the filing cabinet and organise every single sheet of paper, and the minute I've got each part organised, that's fine, I'm completely calm. But I'm only three weeks into my treatment and I would still say it'll take me about another two weeks of quite intense organisation and then if that is when the effects are going to hit me, my own head will be completely clear of the whole thing.

4.2.3 Plan of Analysis

Interviews were audio taped and transcribed for analysis (see Appendix 8 for a full sample transcript). The typed transcripts (in Microsoft Word Format) were

imported into software for the purposes of thematic analysis. This software was NUD*IST (Non-numeric Unstructured Data Indexing Searching and Theorising), (Qualitative Solutions and Research Pty Ltd, 1997). NUD*IST is software that is used to facilitate thematic qualitative analysis. This is a standard approach for developing themes from qualitative material, used within the study to inform the development of a pool of items.

4.3 Results

The themes derived from this material were then examined to formulate specific questionnaire items. The interview transcripts were coded according to the common themes reflected within patient statements during interview. This coding was achieved by reading the transcript of the patient and research utterances. When an utterance contained information that seemed to relate to an identifiable issue this was highlighted in order that other utterances within this trasnscript could be cited alongside all utterances within that transcript with the same thematic link . This way the analysis of transcripts first involved the identification of a theme within a transcript and the act of noting this in order that other thematically similar content from within the same transcript could be noted alongside this theme. As this process was applied to the first transcripts to be examined it meant that as the utterances from within other transcripts were read that utterances from within them could then be linked with all thematically linked utterances from prior transcripts. This way a collection of patient utterances, taken from all of the transcribed interviews and reflective of different themes across patients is collected together. This process of systematically reviewing the content of the utterances within the transcripts, defining thematic categories and

assigning all utterances to one or more of these thematic categories is achieved by using the facilities within the NUDIST software package. Within the software the thematic category is known as a 'node'. A sample of information collected under a node labelled 'Life Review' is outlined at Table 4.6. The complete listing of all utterances collected for this node (illustrating how the utterances from transcripts relating to various patients have all been extracted and gathered together on account of their thematic links) for all participating patients is attached as Appendix 9.

Once the coding of transcripts was complete, the list of nodes and attached text (reflecting the themes that had been identified in one or more transcripts) was printed. The content of these documents was inspected and items were derived from this content, ensuring that whenever possible verbatim quotation was retained. The main aim in using this approach to thematically analyse content was to ensure that questionnaire items could be derived in accordance with actual statements from a range of people with cancer. Clark and Watson (1995) refer to this stage in scale development as being crucial, stating that systematically sampling all potentially relevant content is fundamental at this stage. The item pool should consequently be broader than the target construct, including content that may subsequently be regarded as irrelevant, tangential or not sufficiently related to the construct. As such, they suggest an over inclusive approach. Table 4.6 contains some individual statements made by four different patients. This is reflected by the fact that each section (referred to as 'ON-LINE DOCUMENT') has a unique patient identifier alongside it. Table 4.6 outlines the names that were assigned to each of the nodes representing thematically related content from within the transcripts.

Table 4.6

Example of Patient Utterances Collected with Node Labelled (Life Review)

Node Browser

+++ ON-LINE DOCUMENT: 1001-1052215 (this is the number of the transcript)

[1001-1052215:204-209] (the 204-209 numbers represent the lines where the following appears in the transcript from which it has been extracted)

At the moment not being out doing work, sitting about the house all the time, you start getting bored with just sitting about, you can't go back out to work right away because

you know you're not fit enough yet. If you've been working all your life it's a hard time to stop and just say you're not doing any more.

+++ ON-LINE DOCUMENT: 1005-736823

[1005-736823: 185-190]

Problem. Also, I think you assess your life, and you think no, I've had a good life up to now, maybe I have to do things a different way, but there are things I want to do, and hopefully if my husband keeps well, we're going to do. You've got to look to yourself and decide what's for you. The way I feel so far, I feel well, and God willing ...

+++ ON-LINE DOCUMENT: 1023-1144231

[1023-1144231:233-238]

I suppose it's a quite outlook; having cancer makes you grateful for your health before you had it, which you're inclined to take for granted. In my case, where I never had

much illness, it suddenly strikes home to you that you've got grandchildren, and

you say to yourself 'how long will I see them for'. But fortunately through this treatment it +++ ON-LINE DOCUMENT: 1024-1151415 [1024-1151415:46-51] Probably the outlook - your outlook on life changes somewhat. You think well, today I'm here, we live for today. I tend not to think about the future because you don't know what you've got, so you just live day to day. As such, life becomes a lot easier.

Table 4.7

Names of the Nodes that were derived from Thematic Analysis of Information within Transcripts

Unexpected	Appearance
Reminders	Fighting Spirit
Uncertainty	Reduced Life Span
Expectations	Work
Functional Ability	Religion
Life Review	Treatment Outcome
Information	Acceptance
Hope and Optimism	Support
Effortful Avoidance	Prior Experience
Control	Worry for Others
Trust	
Other Experiences	
Illness Representation	
Understanding	

Table 4.8 illustrates the way in which items for the pool were worded by examining the information contained within the nodes.

Table 4.8

Example of the Way in which Item Content was Derived from Thematically c Coded Utterances

Item: I accept that I have cancer (From Node labelled 'Acceptance')
Well, I'm just one of these people, I accept what's got to be done has got to be done to help you. I don't dwell on it too much; I just accept it and get on with it. I think I have actually accepted that within myself. I don't mean in any kind of morbid way at all, don't dwell on that because it is not good for one's soul .... I can remember both times clearly, when I was given the diagnosis. And I can actually remember that it was just an acceptance. It was such a big deal, but there's not any point in getting upset about it, because there it is. There was no dubiety about it, I had cancer. I don't know, I really don't know. I think a lot of it depends on your own attitude towards life in general, the way you accept something for what it is. I've accepted it for what it is, for what I've got and I've realised that I have to get up and get on with it, and that's it. I think it was getting told that you had cancer. Once I'd learned to accept it I was still down at times .....

Item: Cancer is not as bad as it is made out to be (from Node labelled 'Expectations')
Well it is not as bad as I thought, put it that way. Well I did. Nothing so far has been as bad as I thought it would be. Just the fact that I feel much fitter than I expected. I knew that chemotherapy had quite nasty side effects, and I kept looking for these side effects and wondering if they would come or get worse.

Item: I have lost control of my life because of cancer (from Node labelled 'Control')
What's going to happen next, knowing that you are not the person that is going to be controlling it. You don't get to control how much of this or that, it all has to be done for you. There are a lot of things out with my control at the moment; I don't feel totally in control. Just how I felt. Not really feeling in control of what's happening to me during the treatment. But I feel that I have lost control not only of my physical being but also of my mind.

Item: I appreciate life more because of cancer (from Node labelled Life Review)
.. having cancer makes you grateful for your health before you had it, which you're inclined to take for granted. In my case, where I never had much illness, it suddenly strikes home to you that you have grandchildren and you say to yourself 'how long will I see them for?'

..... and I think also that you decide what is important - I was quite a career person before and now it doesn't bother me at all.

Reappraising life. If you think that you're going to lose your life then you begin to think about what you are here for and what you're trying to achieve.

Item: I cannot escape reminders that I have cancer (from Node labelled 'Reminders')

.. clothes smelled of the treatment all the time. I could smell the drugs and that coming through my pores and everything else.

The last time there was a young girl came in with absolutely no hair, wearing a baseball cap, and I did think 'poor soul'. You see people like that and you think wait a minute, maybe there is something wrong with me here, maybe I have got something - a reminder of it.

.... Everybody you meet, saying how are you getting on, and it's a constant reminder as well, when sometimes you just sort of forget about it and get on with it, it doesn't bother you.

I think honestly to me it's like a life sentence because it's never out of your mind.

Sometimes I get phlegm in my chest, a crackly sort of feeling and just feel that gosh, what's happening sort of thing, I wish it would stop, that kind of thing. If that didn't happen I think I would probably think less of it.

When you're having radiotherapy/chemotherapy you're very conscious of anything on TV or in the media to do with cancer, and cancer charities and cancer shops.

The phrasing of an item for inclusion in the pool is outlined. The node name that this came from is also specified and the individual utterances that were used to influence the phrasing of the item in the item pool are listed. At this

stage particular attention was paid to the generation of item content that related to the construct that the questionnaire was being designed to measure. Items were phrased in a manner that acknowledged the positive and negative effects of cancer related experiences. When all utterances from transcripts had been assigned to nodes, a Senior Research Fellow with experience of qualitative research methodologies inspected the listings of nodes and related patient utterances. She confirmed that utterances were appropriately assigned to an adequate range of thematically organised nodes.

One hundred and thirty-four patients were identified as being potentially suitable for inclusion in this study. Eighty-two of these were identified as a result of case note review. Fifty-two patients were identified as being potentially suitable from records of patients due to attend for elective radiotherapy or chemotherapy appointments. Fifty-six patients were interviewed and consented to have their interviews audio taped and transcribed. The remaining patients elected not to contact the researcher, were excluded by virtue of physical illnesses or it was not possible to trace them within the cancer centre at the time of their return visit. Thirty-one were female.

The final pool of items is outlined in Table 4.9

Table 4.9

The Final Pool of Items that were Generated from Patient Interviews

My cancer philosophy is 'live for today'
Cancer rules my life
It is not fair that I developed cancer
I am going to die as a result of my cancer
I view cancer as a challenge
People are there for me no matter what happens with my cancer
My world has fallen apart because of cancer
Cancer interferes with living my life
I am conscious of cancer all of the time
The things I had planned for my life are no longer options
My thoughts about cancer are out of control
My faith in God will see me through my cancer
Cancer is not as bad as it is made out to be
Cancer has changed every aspect of my life
I wonder if my cancer has spread
I don't have cancer
Other people are nosey when it comes to my cancer
Cancer is not as bad as it is made out to be
My life has been shattered because of cancer
There is no escape from cancer
I accept that I have cancer
I know that I will be cured of my cancer
I have no control over any aspect of my cancer experiences
Cancer is a death sentence
There are some things that are good about having cancer
Knowing that I am in good hands helps me to get through my cancer experiences
Other people do not understand what it is like to have cancer
Everything about cancer is negative
It is best to leave all the cancer decisions to the doctors and nurses
I appreciate life more because of cancer
I must have done something negative in my life to have developed cancer
Cancer is at the root of all my problems

Everything about cancer is bad news
My family will be left without me
Luck will determine what will happen to my cancer
Others I know with cancer have inspired me
Staff in the cancer centre are there to help me in whatever way they can
My world has collapsed around me because of cancer
Other people's reactions to my cancer give me hope
I have lost control of my life because of cancer
Having cancer restricts my life
There are worse things that could have happened to me than having cancer
Cancer makes you focus on what really matters
I cannot escape reminders that I have cancer
Cancer doctors and nurses are there to help me in whatever way they can
All I see around me is suffering because of cancer
Cancer should not have happened to me
Cancer doctors don't really care about what happens to me
I don't know what is happening with my cancer care
My life will never be the same again because of cancer
There is so much about cancer that I do not understand
I have lost my independence as a result of cancer
I am a completely different person because of cancer
I have no control over the course of my cancer

4.4 Discussion

This component of the work to develop a measure of core contextual meaning in cancer can be considered from two perspectives. First, the methodological choices made regarding the scale development process and also the findings as they relate to the identified concerns of the people with cancer that participated.

4.4.1 Method Used to Generate Items

The early stages of scale development involve the need to generate items for inclusion in the initial version of a scale. Some researchers generate these from their experience, from literature (which may or may not include a theoretically derived model to generate items) and from procedures that explicitly aim to facilitate the generation of item content. In some cases it is possible to do this using all of these components. The reliance on interviewing of participants represents a more comprehensive approach to item development than that adopted by some researchers who generate their pool of items solely on the basis of literature review or personal clinical experience. Mahon and Casperson (1997) outlined how questions were added to an interview protocol on the basis of information that was obtained throughout their recruitment process. This approach was not incorporated within the work reported here on the basis that the aim was to generate common themes underlying the issues that were reported by patients.

Although a decision was made to use the content of individual interviews for the generation of questionnaire items, the possibility of using focus groups was considered. Focus Groups have the advantage of enabling more patient experiences to be sampled in less time. However, it was decided that the requirement that patients disclose information on their cancer related feelings and thoughts in the presence of other people, could significantly inhibit the nature of such disclosure due to the personal nature of many of the thoughts experienced by people with cancer. The development of possible questionnaire items on the basis of literature review was considered but ruled

out on the basis of the inherent problems that there are with reaching biased decisions about inclusion and the limited scope to base item content on patient quotes that this method offers.

Having considered and ruled out focus groups and literature review as the preferred methodological approach to item content generation, it was decided to derive the content of the scale directly from the interviews relating to the experiences of people with cancer. Interviewing provided the researcher with a greater opportunity to clarify statements and to explore the thoughts associated with the target construct and observable displays of affect. This would have been impossible if the primary approach to generating item content had been based on the inspection of themes from prior literature and more difficult to achieve within a focus group discussion. The advantages of being able to explore patient thoughts and feelings in this manner (particularly when initial patient statements might not reflect 'deeper' meaning) was a key reason for this being chosen as the primary method for the development of the item pool.

4.4.2 Decisions about Sampling Strategy for Pool of Items

When the decision had been made about the approach that would be adopted for the development of the initial pool of items, this then raised the need to consider the most appropriate way in which to sample the overall population of people with cancer. The approach that was taken with regard to sampling was that of 'sampling to redundancy', a commonly accepted strategy within research that has a qualitative focus and one that is ideally suited for work to develop information for generating items at this the first stage of

questionnaire development. In qualitative research continued interviewing of patients until identical themes begin to emerge in the transcripts of interviews is one of the main outcomes at the end of the research process. In contrast, the emergence of themes here is the first stage in the process of scale development. There are some similarities between the approach that has been adopted in order to develop a pool of questionnaire items and those used in a range of qualitative research projects. These relate to the fact that transcriptions of interviews constitute the raw data, that the identification of themes was used to ensure that items were written for each theme and that the software that was used is one that is commonly used by those engaged in qualitative research. Although these are indeed features of qualitative research studies, the generation of themes to facilitate item generation was not in itself a qualitative research study and did not therefore apply principles and procedures relating to the triangulation of data or approach analysis of themes in accordance with grounded theory, hermeneutics or other qualitative paradigms.

A total of approximately fifty hours of patient interviews were conducted. The decision to spend this amount of time interviewing patients was taken in acknowledgement of the fact that no amount of statistical manipulation during later research phases can compensate for poorly chosen items within an initial item pool (Streiner & Norman, 1995). The number of patients that were interviewed for the purpose of generating items for the item pool may however have been unnecessarily large. Salmon *et al.* (1996) interviewed thirteen patients in the initial phase of their work to generate items for inclusion in the initial item pool for the Life Evaluation Questionnaire. This is approximately one quarter of the number of patients interviewed to develop

the CCMM pool of items. The fact that a large number of patient illness experiences were sampled in this study does however contribute to the confidence that can be placed in the validity and comprehensiveness of the range of issues identified in relation to the examination of cancer related meaning and interpretations.

A number of options were considered for the format of the interviews to generate information for the development of the item pool. Structured and semi-structured interviews containing solely predefined questions were considered but ruled out on the grounds that they did not allow for the exploration of idiosyncratic patient problems and feelings from a cognitive perspective. It was decided to rely heavily upon the researcher's training as a cognitive therapist and to facilitate this process by applying the guided discovery elements of cognitive therapy. The inclusion of this within the interview protocol allowed for the exploration of cognitive aspects of patient problems and/or the emotional and behavioural consequences of their cancer experiences. This way it was possible to focus upon the underlying meaning and interpretations relating to the statements that patients made during the interview. The defining feature of these initial interviews was a desire to access the 'core' of what it meant to have cancer. These interpretations are often outside of the immediate consciousness of patients, though are more easily accessed when questioning is targeted at affect laden statements or when specifically phrased questions are targeted at cancer concerns and problems to elicit cancer related meanings.

In addition to the sections of the interview that contained the opportunity to disclose concerns and elaborate following interviewer questions, it was

decided to include a request to complete sentence stems consisting of content covering issues pertinent to cancer and cancer treatment experiences. This served to provide an alternative method to elicit further cognitive content for exploration through questioning, aimed at identifying the elements of meaning that were present within patient thoughts about cancer.

4.4.3 Results of Content Generation

The 53 items that were produced for the initial item pool reflect the range of thoughts that have been reported in the literature on psychological experiences associated with cancer (Brennan, 2001). However, some of the themes that appeared in the interview content were not related to the core construct that was being considered and which would comprise the core of the measure. Themes that were clearly not related to the core construct were not translated into questionnaire items for the initial pool. A liberal approach was adopted in taking these decisions initially, in order to reflect a broad definition of the construct to be operationalised. This was decided in the knowledge that the subsequent stages of scale development would involve consideration of the comments of an expert group and patients during a field testing phase, allowing further refinements to take place at that stage. Whenever possible phrasing of the items for the pool were based on the precise wording of the comments that were made by some of the participants. To increase construct relevance, all items were phrased to maximize references to cancer and the personal significance of cancer.

4.5 Conclusions

This Chapter has outlined how the underlying meaning behind the experiences of a heterogeneous sample of people with cancer was assessed. Themes from their statements were used to develop an initial range of items for inclusion in the first draft of the CCMM.

Chapter 5 Further Developments - Peer Review and Field Testing

5.1 Introduction

This Chapter addresses the next phases in the development of a self-report measure of core cancer meanings. An initial pool of items has been outlined, though no decisions had been made at this stage with regard to the layout and response format to be used with the questionnaire. Despite the fact that items were derived from a large sample of patients' interviews, the pool of items had not been circulated to any other people for comment at that time. The next stage of scale development involved content validation from an expert panel. The process of examining the way in which items had been phrased and the impact of this on patient understanding of content is also a vital (and sometimes overlooked) component of scale development. The application of this stage will be described in this Chapter.

One of the primary considerations in the further development of this measure was consideration of the dimension (e.g., level of agreement, extent of applicability, frequency of occurrence) that would be assessed for each item within the measure. When dimension of assessment was decided, the number of response choices for each dimension and the wording that would be used for each also needed to be considered.

5.1.1 Deciding What Response Dimensions to Include

Most measures of cognition assess degree of conviction/level of agreement with each item. The frequency with which patients experience negative thoughts and beliefs is also assessed as a distinct dimension with some measures such as the Automatic Thoughts Questionnaire (Hollon & Kendall, 1980). Glass & Arnkoff (1997) have outlined how the assessment of thought

frequency can result in problems relating to interpretation of a score on this measure. This is illustrated by the fact that two patients could have the same high score, one on the basis of experiencing many thoughts occasionally and the other by experiencing a smaller number of thoughts more frequently. A score of 90 on this measure might indicate that a patient experiences all 30 thoughts outlined on this measure 'some of the time'. A score of 86, which is of a similar magnitude, might indicate responses that reflect 16 thoughts that were never experienced and 14 that were present 'all of the time'.

Some measures address these problems of interpretation by including more than one rating dimension. It has also recently been suggested that other dimensions (such as controllability and intrusiveness) may be important factors in considering affective responses associated with cognitions (Papageorgiou & Wells, 1999). However, the inclusion of response formats for two dimensions of each item (e.g., frequency and agreement) can cause problems in that the factor structure for each set of responses often does not yield the same solution (Wells, 2000a: personal communication).

Many of the concerns reflected within the thoughts of people with cancer might be experienced frequently, though frequently thinking about them does not necessarily equate with experiencing distress. Traditionally, cognitively based therapies have sought to identify and modify level of conviction in interpretations and beliefs and to enable patients to reduce their distress. In view of the problems that have been referred to in interpreting measures of thought frequency, multiple response dimensions and the traditional emphasis in cognitive therapy on level of conviction and agreement with thoughts, it

was decided to develop a measure of cancer meaning that assessed level of agreement.

5.1.2 Deciding upon the Response Format

Given that it was decided that the measure should elicit responses on level of agreement with each item, decisions had to be made on the response format within this dimension, principally the number of choices that would be provided for each item and the response labels that would be used for each one.

Several response formats that could be used to indicate varying levels of agreement were considered. These reflected a range of different possibilities for the number of responses and also the way in which each response would be labelled. Some existing self-report measures of cognitions were identified for the purpose of providing examples that could be incorporated into the process of identifying the response dimension for the new measure. This included the Health Locus of Control Scale (Wallston *et al.* 1987) which has response choices that reflect different levels of agreement that are labelled as 'Strongly Disagree', 'Moderately Disagree', 'Slightly Disagree', 'Slightly Agree', 'Moderately Disagree' and 'Strongly Agree'. In this respect the Health Locus of Control Scale is typical of self report measures focused upon agreement in that it consists of response labels which consist of responses to differentiate between agreement or disagreement and each option has a preceding quantifier to indicate the strength of agreement - e.g. slightly or moderately. Another example of a questionnaire with a response format focused on level of agreement is the Metacognitions Questionnaire (Wells, 2000). This consists of four responses that are labelled 'Do Not Agree', 'Agree

Slightly', 'Agree Moderately' and 'Agree Very Much' and was selected as the response format for use in this study.

Self-report measures that consist of a choice between an odd number of responses are more likely to promote responding to the middle position (Streiner & Norman, 1995). For questionnaires that are focused on assessing level of agreement and with this number of choices, there is a tendency to label the middle response as 'Neutral' or 'Neither Agree nor Disagree'. This can lead to a propensity toward 'neutral' responses, particularly among those respondents who may be dispositionally predisposed toward uncertainty. Inordinate use of the middlemost scale point (Dawis, 1987) can be avoided by using an even number of response choices. In addition to whether the total number of response choices is an odd or even number, the issue of overall number of response options needs to be taken into account. A larger number of response possibilities (such as in self report measures that have nine response choices) can compromise validity as a result of the fact that random responding is more likely to occur when respondents are faced with a larger number of possible responses. In view of the previously expressed importance of developing a self-report measure that can be utilised by clinicians, and the decision to focus on agreement as the sole response dimension for the new scale, an even number of responses were chosen and the total number was limited to four.

Comparative methods such as Thurstone's method of equal appearing intervals or Guttman scaling were considered as alternative ways in which responses could be scaled. They tend to be particularly appropriate when there is a need to disguise ordinal properties of a scale and where it may be necessary

to guarantee interval level measurement. Given that these were not important considerations and the fact that comparison methods are not regarded as clinically useful, it was decided to explore the options regarding direct estimation methods. At this stage a measure that required respondents to indicate their level of agreement on the basis of a four point forced choice format with response labels of 'Do Not Agree'; 'Agree Slightly'; 'Agree Moderately', 'Agree Very Much' was chosen. An initial draft version of the measure that included the pool of items and a response format of four responses to reflect differing levels of agreement was established.

5.2 Peer Review Phase

The second element to this stage in the development of the measure was to elicit information from experts in clinical psychology and psychosocial oncology regarding the content, structure and format of the measure. Ensuring that new assessment measures have adequate face validity is an important component of the process of validation. Eliciting the comments of an expert panel can also result in the generation of issues that will be crucial in further stages of measure development, particularly field testing.

5.2.1 Method

The first draft of this measure was sent to ten clinicians with a request for comments on item content and any other issues that respondents thought may relate to face or content validation. Background information was provided within a covering letter on the aim to develop a generic meaning based measure that did not specifically relate to cancer site or treatment modality (see Appendix 10). These clinicians for this phase were chosen on the basis of

their expertise in psychosocial oncology, cognitive therapy or adult clinical psychology. Drs. Moorey and Greer are the authors of a major textbook on a cognitively based psychological therapy for people with cancer (Moorey & Greer, 1988). Professor Scott and Dr. Davidson are internationally acclaimed cognitive therapists and Drs. Brennan, Harvey & McNair experts in psychosocial oncology. Dr. Merluzzi is an academic psychologist with experience of developing self-report measures in psychosocial oncology (Merluzzi *et al.* 2001). Mrs Wight was the Head of an NHS Clinical Psychology service and was chosen in order to elicit the opinion of a clinical psychologist working in adult mental health.

5.2.2 Results

Nine responses were received from clinicians. The feedback received on this included general comments about the measure (e.g., layout, instructions for completion) and specific feedback on items (e.g., issues relating to item wording and content). This feedback is reproduced in Table 5.1.

Table 5.1

Feedback Received from Peer Review Group on First Draft of Measure

Name	Comments/Feedback
Dr. James Brennan Consultant Clinical Psychologist Bristol Oncology Centre	Critically important area to look at as central to clinical work Questionnaire reads like 'liturgy of disaster' Covers central issues Missing theme is "amputation of the future" e.g., unable to look to the future unable to make plans for fear of tempting fate Missing theme is existential loneliness

	e.g., no one else can really understand unfolding experiences Item 49 ambiguous - +ve or -ve? Items 20 and 32 could cause problems with people saying accept that I had cancer - I don't have cancer now - timing of administration may prove crucial Item 14 ambiguous - ? Treatment related rituals as opposed to core values and relationships Some items seem to drift from the notion of core beliefs - e.g., Item 17 and 33
Dr. Kate Davidson Senior Lecturer in Clinical Psychology University of Glasgow	Some items are very similar to others Wondered about need for more items which are concerned with others e.g., People don't know what to say about my cancer People ask how I am but avoid talking about the cancer People talk about my treatment but not about the cancer I think other people think I am going to die People behave oddly around me I am afraid that other people will write me off because of my cancer People feel sorry for/pity me because of my cancer Items relating to others which are positive e.g., I think that people are interested in me, not my cancer Self/others may be an important factor in adjustment
Dr Stirling Moorey Consultant Psychiatrist in CBT South London and Maudsley NHS Trust Psychotherapy Unit	The questionnaire covers the important areas, particularly dysfunctional beliefs Reads very well and most patients would find it easy to complete Could imagine a questionnaire that just focused on dysfunctional or unhelpful beliefs (cf DAS for cancer patients) If cover both - what should the balance be in a questionnaire of this kind? MAC: Fighting Spirit and Antonovsky Sense of Coherence Scale

	? how much focus on metacognitions (ref to item 11) range of beliefs about what constitutes good coping could be several different cognitive elements - e.g., attributions of control, beliefs about emotions, attitudes on prognosis, treatment and support increase the items up to 100 and after factor analysis cutting them down to 40 or so item 15 is not a belief? change to my cancer is going to spread item 4 may be realistic for some with advanced disease item 30 is a little vague - replace the word 'negative' with 'bad' or 'wrong' inclusion of item relating to denial/avoidance raises issues - extent to which belongs in a meanings measure. Could add in items related to this - 'People exaggerate the seriousness of my illness' makings of a questionnaire which will be extremely valuable for clinicians working in this area
Mrs Zena Wight Consultant Clinical Psychologist CCPS Strathdoon House	Suggested changes to the front page: Having cancer means different things to different people. This questionnaire contains a range of beliefs that people can hold about their cancer. The purpose is for you to identify the beliefs that you hold about your cancer. Each number in the right hand column refers to a different level of agreement with each belief/statement. 0 indicates that you ..... For example: Suggestion to remove the heading ITEM NUMBER Need to resolve the confusion between thoughts/beliefs/statements Some of the items are generic and others are personal to experiences of cancer Remove the heading 'beliefs' within the main body Is Item 23 too challenging?

Dr Peter Harvey Consultant Clinical Psychologist The Cancer Centre Queen Elizabeth Hospital Birmingham	Might it be helpful to identify that the statements within the questionnaire have been collected from patients? Items 36 and 44 are very similar Items 37 and 18 are very similar
Dr Tom Merluzzi Department of Psychology University of Notre Dame Indiana USA	Suggestion that many items are thoughts and not beliefs - 'thoughts is a safer option'. 'Your Thoughts about Cancer' Suggested addition of the word 'might' ..... ' you might have about your cancer' When explaining the options for scoring the measure the different responses could be listed: 0 Do Not Agree 1 Agree Slightly Etc. Change to read each thought (remove item) and to read with each thought (remove belief) Item 22 - does not distinguish control over disease from control as part of coping Item 25 - ambiguous with regard to whether refers to physician, spouse, support system etc. Item 33 - suggested clarification to read 'I am worried that my family ....' Suggested additional items: I am better off than most people with cancer I know why I got cancer I believe I have some control over my cancer Cancer affects my work Balance of positive and negative thoughts - refer to Schwartz and Garamoni's States of Mind hypothesis. Good to have equal numbers of positive and negative statements
Dr. Steven Greer Consultant Psychiatrist St. Raphaels Hospice	Measure has excellent face validity and should prove valuable 'I have no criticisms'

Dr. Lesley McNair Clinical Psychologist Beatson Oncology Centre Western Infirmary, Glasgow	'very comprehensive' ? alternative to question 38 such as: Other people's reactions to cancer make me pessimistic.
Prof Jan Scott Professor of Psychiatry University of Glasgow	Language needs be modified to take account of the average reading age of the population (e.g., item 1 re cancer philosophy) Item 4 - does this need a time frame? (I am going to die as a result of my cancer') Item 8 - needs to be more specific and take account of the fact that someone with recent diagnosis may well have life disruption due to requirements relating to Treatment attendance Item 9 - understanding? rephrase as: 'I am preoccupied by my cancer' or 'I think of cancer all the time' Items 7 and 18 - identifying the same issue Item 24 - what is this trying to tap into? Item 30 - ? changed wording as could be something negative or something for which they think they should be punished There is no item about the possibility of cancer recurrence - some people my/my not believe that they have been cured; understand the risks of further problems

Expert respondents were generally positive about the scale and provided comments that supported both content and face validity of the measure. Some peer reviewers suggested additional content. This occurrence may initially seem to conflict with the earlier statements that sampling to redundancy within themed comments was adopted. Issues that were highlighted by peer reviewers were taken account of if they related to item content from the core construct or the layout of the measure. Five items were

removed following receipt of peer reviewer comments. Table 5.2 outlines the items that were removed on the basis of this peer review process and the justification for their removal (denoted in italics within the table).

Table 5.2

Items Removed from the Pool of Items Following the Peer Review Process

Item Reason for Removal
I am going to die as a result of cancer *This is a factual statement for some respondents*
Other people are nosey when it comes to my cancer *This is not related to the target construct of the measure*
My family will be left without me *This is a factual statement for some respondents and is unrelated to the core construct*
Staff in the cancer centre are there to help me in whatever way that they can *This is similar to the item 'Cancer doctors and nurses are there to help me in whatever way they can'*
My life will never be the same again because of cancer *This is ambiguous*

Two items were removed on the basis that they represented factual issues and did not therefore contribute to understanding patient interpretations of actual experiences. Other items were removed as they were not related to the target construct and the remaining items because peer reviewers highlighted ambiguities.

Table 5.3

Items Rephrased from the Pool Following the Peer Review Process

Item -> Rephrased Item Reason for Rephrasing
I am conscious of cancer all of the time -> I think about my cancer all of the time *Rephrased to make emphasis on thinking clearer and emphasis on patient's experience of cancer*
I must have done something negative in my life to have developed cancer -> I must have done something wrong in my life to have developed cancer *Rephrased as ambiguous*
Cancer makes you focus on what really matters -> Cancer makes me focus on what really matters *Rephrased to emphasise patient's experience of cancer*
There is so much about cancer that I do not understand -> There is so much about my cancer experiences that I do not understand *Rephrased to emphasise patient's experience of cancer*

Four items were rephrased following receipt of peer reviewer comments (Table 5.3). Most of these items were rephrased to emphasise cancer, thus reinforcing the aim of focusing on cancer specific elements of their experience (a key element in the assessment of situational meaning). Seven additional items were added on the basis of suggestions that were made by the expert group - these items were 'I don't plan for the future because of my cancer'; 'Other people exaggerate the seriousness of my cancer'; 'I am better of than most people with cancer'; 'I have some control over the course of my cancer'; 'Other peoples reactions to my cancer make me pessimistic'; 'I have no future because of cancer'; 'I keep thinking my cancer might come back' and 'I don't' plan for the future because of my cancer'. Peer reviewers also made comments that, although not leading to the removal or rephrasing

of items, raised issues that required further exploration. This feedback was incorporated into a field testing protocol in order that respondents could provide comments on the issues that had been raised by peer review. The list of issues identified during the peer review process that were incorporated into this protocol are highlighted in Table 5.4.

Table 5.4

Issues from Peer Review Incorporated into Field Testing Protocol

Clarify patient understanding of 'My cancer philosophy is live for today'
Do 'My world has fallen apart because of cancer'; 'My life has been shattered because of cancer' and 'My world has collapsed around me because of cancer' assess the same issue
How do patients understand 'Cancer interferes with living my life'
Clarify patient understanding of wording in 'Cancer has changed every aspect of my life'.
Clarify patient understanding of 'I wonder if my cancer has spread'.
Determine patient thoughts and feelings about the inclusion of 'Cancer is a death sentence'.
Clarify patient understanding of 'There are some good things about having cancer'.
Clarify patient understanding of 'Knowing that I am in good hands helps me to get through my cancer experiences'.
Clarify patient understanding of 'I don't have cancer'.

Peer reviewers suggested that respondents might misunderstand several items and these observations were also incorporated into the protocol for field-testing, to gather more information. An example of this was the concern that had been expressed that patients would be distressed at the inclusion of the item that referred to cancer as a death sentence.

5.2.3 Conclusions

It was clear that there was a consensus from the small expert panel of reviewers regarding the face validity of the measure and no major concerns were consistently reported about item content and/or the structure of the proposed measure. It would have been possible to elicit similar information from a larger group (perhaps a national group of clinical psychologists working in oncology). There was no quantitative measurement to assist with the description of the respondents views of this measure and this too would have been desirable and enabled a more systematic evaluation as to whether the measure was acceptable on important dimensions such as the item coverage and wording. This could have elicited ratings on relevance to the core construct, appropriateness of choice of response stems and the wording of individual items. The comments that were provided by professional peers were invaluable in considering the information that would be required from patient respondents in terms of the further development and refinement of the measure. The next stage that was planned for the further refinement of the measure was field testing with a group of people that had recently experienced cancer and/or cancer treatment in order that information could be elicited on each item and responses gathered on issues identified at peer review.

5.3 Field Testing of the CCMM

5.3.1 Introduction

Clark and Watson (1995) have suggested that during scale development, proposed formats should be pilot tested for the purpose of obtaining

Table 5.5

Structure for the Field Testing Interview

Explanation of the purpose of the interview
Patient completes the questionnaire (notes taken re pertinent observations/comments made)
Three items were randomly chosen for each of the possible response stems and patients were asked to elaborate on their reasons for answering in the way that they did
Section to elicit information on issues generated from expert review
Patients asked about relevance, understanding, reactions to completion of the questionnaire

Patients were asked to elaborate on their responses to the CCMM. They were also asked specific questions that had been included to gather data on issues identified during the peer review phase of questionnaire development. A sample of the patient responses to the request for elaboration for some of the items included in the field-testing phase is outlined in Table 5.6. The full details of patient responses to this field-testing phase are outlined at Appendix 13.

The responses provided by patients about their reasons for endorsing the items that they did were extremely supportive of the content validity of the constituent items. This provided confirmatory evidence to support the work undertaken during the preceding phase of scale development. In addition to recording the statements that participants provided to explain their responses, general observations regarding statements made during field testing were also recorded throughout the administration of the measure (see Table 5.7).

Table 5.6

Examples of Elaborations Provided by Patients for Two Items

Item	Example of Patient Elaboration
I appreciate life more because of cancer	I have always appreciated life, it is a gift It makes you appreciate the things that you have got and how you don't think about it until you are going to lose them Something you think that is not going to happen and makes you appreciate things I don't feel that the cancer that I had has made any difference to my life Yes, I think it does. It is the fear initially that you are going to die and the thought to get out there and do things
My faith in God will see me through my cancer	I don't believe in God I have conflicting thoughts, if there is a God then why did he let me take it I am not very religious. I believe there is a God and something is looking after me Whether Christian or not, whatever happens in my life may be this is the only time that you turn to God and ask what you have done wrong in life and that this should happen

Table 5.7

Sample of General Observations Made During Field Testing

Patient asked 'Is this based on how I feel at this moment in time?'
After reading a few items, the patient said " I will make special note of the ones that I want to qualify in some way"
Patient having to repeatedly look sideways to check responses attached to each stem

Patients were also asked specific questions to elicit information on the themes that had been identified by peer reviewers. These questions are outlined in Table 5.8 and are based on the issues outlined at Table 5.4.

Table 5.8

Sample Components from the Field Testing Protocol

One of the items from the questionnaire was 'My cancer philosophy is 'live for today' - tell me what you understood this to mean?
The questionnaire included the following: 'My world has fallen apart because of cancer'; 'My life has been shattered because of cancer' and 'My world has collapsed around me because of cancer'. Do you think that these items are different? If so, in what way so you see them as being different?
The questionnaire had an item 'cancer interferes with living my life'. What sorts of things did you think this was asking you about?

Patients attending the Beatson Oncology Centre were invited to participate in the field-testing phase. They were provided with an information sheet on the research and given an opportunity to ask questions before deciding whether to participate.

5.3.3 Results

Seventeen patients participated. There were no refusals to participate in this phase of the study. Four patients had breast cancer, three patients lung cancer and ten patients had colorectal cancer. On the basis of the information that was obtained from these three sources (general observations; elaboration of item responses and answers to specific questions) further revisions were made to the measure. These revisions consisted of the removal

of some items from the pool and the rephrasing of others. Eleven items were rephrased and 16 items were removed (see Tables 5.9 and 5.10).

Table 5.9 Items Removed from the Item Pool Following Field Testing

Item Reason for Removal
The things I had planned for my life are no longer options *This implies that treatment is palliative*
People are there for me no matter what happens to my cancer *The majority of respondents endorsed this*
There is no escape from cancer *Responses suggested that respondents had a more global understanding of this statement that related to cancer incidence and prevalence, not the personal implications of cancer*
Knowing that I am in good hands helps me to get through *The majority of respondents endorsed this*
Everything about cancer is negative *Responses suggested that understanding was too global*
It is best to leave all cancer decisions to the doctors and nurses *Not related to the target construct for the measure being developed*
Cancer is at the root of all my problems *The majority of respondents did not agree with this item*
I don't have cancer *Removed as respondents confused this with stage in the cancer illness trajectory*
Other people exaggerate the seriousness of my cancer *Removed as responses more related to other's experience that respondent*
My world has collapsed around me because of cancer *Respondents believed that similar meaning to item on 'fallen apart'*
Having cancer restricts my life *Response is more concerned with functional ability than meaning*
Cancer doctors and nurses are there to help me in whatever way they can *The majority of respondents agreed with this item*
All I see around me is suffering because of cancer *The majority of respondents disagreed with this item*
Cancer doctors don't really care about what happens to me *The majority of respondents disagreed with this item*
There is so much about my cancer that I do not understand

Rephrasing of another item makes this item redundant
I have lost my independence because of cancer *Related more to functional impact than meaning*

Some items were removed as the majority of respondents endorsed the same response for an item. Others were removed because patient responses suggested that item content was not interpreted in a manner consistent with the intended target construct underlying the measure.

Table 5.10

Items Rephrased Following Field Testing

Item -> Rephrased Item Reason for Rephrasing
Cancer is a challenge -> Having cancer is a challenge to me *To make this item self referent and not generic to cancer experiences*
My faith in God will see me through my cancer -> My faith will see me through my cancer *God removed to account for those with no specific religion but who talked of spirituality*
I accept that I have cancer -> I accept that I have had cancer *Changed to account for the fact that although ongoing cancer experiences (e.g., chemotherapy) patient's considered that cancer was a past event*
I know that I will be cured of my cancer -> I think that I will be cured of my cancer *Changed in light of comment that 'know' seemed to express this with too much certainty*
I have no control over any aspects of my cancer experiences -> I have control over my cancer experiences *Rephrased to change balance of positive and negatively valenced items*
There are some good things about having cancer -> Some good things have come from my having had cancer *Rephrased to clarify that benefit is from having had cancer and to emphasise personal*

experience
I am better off than most people with cancer -> I am more fortunate than most people with cancer *Rephrased to minimise confusion about financial status*
Cancer makes you focus on what really matters -> Cancer has made me focus on what really matters in my life *Rephrased to refer more to personal experience and specifically in life*
I don't know what is happening with my cancer care -> I don't understand what is happening with my cancer care *Rephrased to emphasise understanding as opposed to information*
I am a completely different person because of cancer -> I am a completely different person because I have had cancer *Rephrased to emphasise personal experience dimension*
I keep thinking that my cancer might come back -> I keep thinking that my cancer might have spread/come back *Rephrasing to combine other item regarding spread*

Most of the decisions that were made regarding the rephrasing of items were made to increase their relevance to the target construct. Data suggested that respondents were not upset by the questionnaire and provided responses that suggested that they were aware of the construct that was being assessed. The responses of patients to the question about what they thought the questionnaire was measuring are outlined in Table 5.11.

Table 5.11

Responses to 'What did you think that questionnaire was measuring?'

Comment Number	Comment/Observations
1	I don't know - I have accepted it, others might not
2	Probably to see how stable someone is during cancer treatment, whether they are coping. To see if it has affected them mentally in any way
3	How to handle other peoples problems, you've got to be positive, what is for you will not go by you
4	How you feel about cancer as an illness as well as having the illness - how you view it
5	Designed to measure the mental effects on emotions and whether you fully understand the implications of having a terminal illness.
6	My attitude about having cancer
7	Peoples attitudes to cancer and how they deal with it psychologically. How much their state of mind helps them in treatment and how well they are doing.
8	Trying to get patients outlook on their problems
9	Trying to establishing (sic) how reacting to cancer - the impact on life and how looking to the future - everyone's conception of cancer will be different
10	Treatment or spread of the illness
11	How you feel about the whole thing of having cancer
12	Peoples mental attitude to the fact that they have or have had cancer, their reaction. It is designed to get a more positive response from people whom it destroys mentally
13	I think it is great. It gets the truth out of you and you can see what you are thinking about cancer, whether you worry about it
14	I think it was to get a reaction. It gets to the inside of your thoughts, you can't hide anything. I think a lot of people will show emotion filling it in.
15	Whether the patient has a positive attitude to fighting cancer or not or whether they are resigned to accepting that this is the end for me
16	How people are reacting to being told, that they have it. How they are coping with it.
17	It was assessing your thoughts about cancer from start to finish. From when you got it to now and how you reacted. My outlook is positive.

The draft measure received further validation during this phase in that the majority of respondents identified the emphasis on cognition associated with cancer experiences - described by them as 'attitude, 'view' or 'thoughts' about cancer. Respondent 10 did not mention anything of relevance to what

this measure assessed. If the remaining 16 respondents had provided responses to this question which suggested that they did not appreciate that the questionnaire assessed cognitions then this would have been a concern. Because this was not the case, this anomalous response of one respondent did not substantially alter the conclusion that this measure had face validity.

On the basis of field testing a further 16 items were removed (see Table 5.9), leaving 39 items for retention. Seven of the items that were removed as the answers of respondents suggested that they had not been interpreted in accordance with the definition of meaning being applied, six were removed as the majority of respondents endorsed the same response, two on the basis of responses that suggested patients believed items to be assessing the same element of meaning and a final item on the basis of ambiguity. An additional item was added 'My life has more meaning because of cancer' as it was felt that this had been implied within the statements of some field testing participants but not represented within the 39 items that remained. The 40-item version of the CCMM is reproduced at Appendix 14.

5.3.4 Preliminary Conclusions

The phase that has been described outlines the decisions that were made regarding scale dimensions and response format and the work that has resulted in further refinements on the basis of responses from a panel of experts and a sample of patients. These amendments were either related to ensuring that wording reflected the core construct or when the item content seemed too global, rewording to make it explicit in relationship to cancer. This phase in scale development has provided very important confirmatory

evidence for face and content validity and also evidence that can be used to respond to some of the issues and concerns raised during peer review.

5.4 Discussion

The phases that have been outlined here largely relate to the content validation of the CCMM, representing the preliminary steps that need to be implemented before examination of the measure and its psychometric properties. Face validity was shown to be excellent in that the measure appears to be assessing components of situational meaning. This is a subjective judgement, though the views of expert reviewers are typically cited as evidence (Streiner & Norman, 1995). Expert reviewers and patients provided good evidence for this. Content validity is a related construct that is more concerned with whether all of the necessary components of situational meaning are reflected in the measure. The focus of refinement of item content at this stage related to the need to remove and rephrase items. The issues that were raised by this stage of the development of the measure will now be discussed, first from the perspective of refinement and revision of item content and then the benefits of including a field testing phase will be outlined.

5.4.1 Refinement of Item Content

Clark and Watson (1995) have argued that the processes involved in scale construction are iterative and involves "several periods of item writing". The benefits of undertaking peer review and field testing phases have mainly been with regard to focusing the coverage of the target construct. The process of identifying items that require rephrasing to increase relevance and/or removing items that are not sufficiently relevant to the target construct has

also been possible. As with all of the phases outlined in this and the preceding Chapter the iterative stages of development that have been described have been instrumental in reaching a clearer understanding of the core construct. This is vitally important. Clark and Watson (1995) have suggested that many attempts to develop assessment measures for psychological constructs have produced measures that are saturated with the pervasive dimension of negative affectivity or neuroticism.

In view of the considerable emphasis that was placed on developing the pool of questionnaire items from detailed patient interviews it was considered important to elicit the views of clinicians and patients on this initial item pool. This is not something that is always included within the approaches adopted by other researchers involved with scale development. It proved crucial in this work in that it provided support for the majority of the items that had been developed from the initial transcribed interviews. It was also possible to rephrase and remove items on the basis of the comments and, perhaps most importantly, to generate the content of a protocol for field-testing.

The membership of the peer review group could have been larger. There are a number of UK based (e.g. British Psychosocial Oncology Society) and international (e.g., International Psycho-Oncology Society) professional organisations that, with hindsight, it would have been useful to engage in discussions about the initial item pool. Consideration of the range and phrasing of item content could also have been considered from a quantitative perspective, with respondents being asked to rate points such as the relevance and clarity of the items that were chosen. The decision to remove

and rephrase items was not subject to discussion with a wider reference group and, although explicit notes were made about the reasons for such changes, it would have strengthened this aspect of the method if the refinement of item content was a process that had been conducted more collaboratively with an expert panel of reference.

5.4.2 Benefits of Field Testing

The approach that was undertaken in field testing was based on the approach proposed by the European Organisation for Research and Treatment in Cancer (EORTC) regarding the development of quality of life assessments (EORTC Quality of Life Study Group, 1998). This provided a framework within which to consider the focus of questioning for each item. The EORTC guidelines suggest that questions focused upon whether respondents found the questions annoying, confusing or upsetting should be included. Questions are asked about items on the basis of the answer of each respondent, aimed at eliciting data on the experiences that were utilised in arriving at a response for that item. The guidelines suggest that for questionnaires with more than 20 items that similar questions should be asked regarding the overall module. Although the field testing module did not follow the precise approach outlined in the EORTC guidelines, the generic principles of seeking patient responses about distress or confusion and allowing for elaboration on item content across all response options was adopted.

This level of attention in connection with the field testing phase is rarely implemented in the early stages of scale development and has not been reported by any of the measures that were outlined in Chapter 3 on global or situational meaning. The opportunity to ask patients directly about the issues

that had been raised by the expert group was invaluable in being able to decide upon how to further refine item content and in providing supporting data for the face validity of the CCMM. Specific responses enabled decisions to be made regarding the removal and rephrasing of individual items, further contributing to the face validity of the measure. The useful nature of the data that was collected during field testing on item content also raises the issue of whether it may have been helpful to include field testing to guide the initial decisions that were taken about the response format.

The nature and extent of the rephrasing that was possible reinforces the importance of ensuring that the item content is reflective of the core construct that is being assessed. The potential for psychological assessments to cause distress among patients has sometimes been expressed within psychosocial oncology. These data from field-testing do not support this. Even directly phrased questions about distressing issues such as incurability of cancer did not unduly distress patients.

5.5 Preliminary Conclusions

This Chapter has outlined the work that was undertaken to take an initial 54 item version of the CCMM, and on the basis of peer review comments and field testing interviews with patients, refine and rephrase item content to increase construct relevance. The development of a pool of items, formulation of response dimension and content, application of peer review and field testing have resulted in a version of the CCMM that can now be subject to closer scrutiny on the basis of psychometric performance.

Chapter 6 Psychometric Analysis of the Core Cancer Meanings Measure

6.1 Introduction

The face and content validity of the new measure have been established within the first phases of scale development, reported in Chapters 4 and 5. This Chapter will begin to examine the inter relationship of the remaining items for the purpose of establishing internal consistency and the performance of items according to accepted psychometric properties, with particular emphasis on developing an understanding of the construct and measurement of discrete elements within it. Details will be outlined on the psychometric performance of the items that have been selected for inclusion. Reasons for excluding other items and the initial stages of construct validation will then be outlined. The final version of the CCMM will be outlined at the end of this Chapter.

6.2 Method

6.2.1 Procedure

For the purposes of this phase of the development of the CCMM recruitment was extended to Ayrshire and Arran Acute Hospitals NHS Trust. Ethical approval was sought from and granted by Ayrshire and Arran Research Ethics Committee (see Appendix 17). Information sheets and consent forms were written for use at the Ayrshire sites and in accordance with the Research Ethics Committee guidance (see Appendices 18 & 19). Cancer Clinical Nurse Specialists agreed to become involved with the recruitment of patients. Ten further members of Consultant medical staff agreed to take part in the study and completed declarations of agreement, indicating that they were happy for patients under their care who provided the appropriate written consent to

take part. The recruitment of patients with colorectal cancer was also later extended to Gartnavel General Hospital in Glasgow (subject to the ethical approval already granted by West Glasgow Hospitals NHS Trust). Four Consultant Surgeons from this hospital agreed to participate in the study. The Ethics committee had already approved the extension of the research to cover patients under the care of other members of the Consultant body within this same Trust. It was not felt that it was necessary to inform the ethics committee of this new recruitment site. The arrangements for recruitment within the Beatson Oncology Centre were as for earlier phases of the study.

Patients were invited to participate by the researcher or a member of staff involved with their clinical care. Given that the aim of this phase of the study was to recruit as many patients as possible within the time available (due to the intention to use multivariate statistics at a later stage) several clinical staff with an interest in the research were issued with packs of questionnaires and consent forms in order that they could assist with recruitment. The General Health Questionnaire -12 Item Version (GHQ-12)) (Goldberg Williams, 1988) was administered along with the CCMM. Patients whose responses on the GHQ-12 were above the threshold for the potential presence of clinically significant psychological disorder were contacted by the researcher for the purposes of conducting telephone screening of the potential existence of clinically significant psychological symptoms or disorder.

6.2.2 Sample

The inclusion criteria for this phase of scale development were that patients should be aged 18 years or over, have and be aware of a confirmed diagnosis of primary breast, lung or colorectal cancer. Patients were excluded from the

research if they were considered to be too physically ill to participate and/or there was evidence of rapidly deteriorating physical health status. Patients with acute confusional states and or cognitive impairment were also excluded.

6.3 Plan of Stages in Psychometric Development

First, analysis was undertaken to determine the item-response distribution for each item and in accordance with important clinical and disease characteristics. This was followed by structural analysis to determine which items had to be eliminated from the remaining item pool. Internal consistency analysis is the most widely used method that is used for this process of item selection (Clark & Watson, 1995). The aim of this analysis was to reduce the items to provide a shorter, internally consistent measure that would extend theoretical understanding of contextual meaning processes, but also act as a useful clinical tool for the identification of meanings and to use this understanding to promote more adaptive meanings among those with cancer who have experienced incapacitating distress or psychological problems.

The decision to retain items was made upon the basis of the extent to which items met predefined criteria. These will be outlined in the following sections. Because the aim is to produce a measure that will reflect common themes across common tumour sites, distribution of the responses of patients was taken into account in deciding on which items to remove. The inter-relationships between items and with the overall scale was considered thereafter. The test-retest reliability of the CCMM items will be outlined. The responses to items that remained after excluding those with low test retest

reliability were analysed using exploratory principal components analysis. This will be outlined. This resulted in a short questionnaire for the assessment of the core cancer specific meanings relevant to the experiences of the patient sample.

6.4 Results

6.4.1 Descriptive Statistics

Two hundred and eighty questionnaires were issued to clinicians that had agreed to be involved in this phase of the project. Using the information that was returned by clinicians, 149 questionnaires were issued to patients and there were eight patients who declined to participate. The clinical characteristics of the sample are outlined in Table 6.1. Data were not available for the entire sample. This was due to problems with accessing medical records of these participants within the timescale allocated for review of and access to medical records. Information on pathological diagnosis was extracted from the patient's NHS case notes. Clinical status was classified according to the primary site of the tumour and the extent to which there was evidence of spread from this site. The classification that was used was 'localised', 'locoregional', and 'metastatic'. The number of participants where data were available is denoted after the percentage figure in parentheses. 35 were male (27%, n=130). 68 participants had a primary breast tumour (52%, n=132), 21 had a primary lung tumour (16%, n=132) and 42 patients had a primary colorectal tumour (31%, n=132) and 1 patient had an unknown primary tumour (1%, n=132). Fifty-five patients had localised disease (47%, n=117), 39% had locoregional disease (33%, n=117) and 23 patients had metastatic disease (20%, n=117). The date of birth and date of questionnaire

completion were available for 101 participants. Age was calculated from these dates. The mean age of participating patients was 60.4 (sd 11.4, range 32 to 100).

Table 6.1

Clinical Characteristics of the Patients that Participated in the Validation Sample

Tumour Location	Localised	Locoregional	Metastatic	TOTAL
Breast	33	25	4	62
Lung	11	3	3	17
Colorectal	11	11	15	37
Unknown primary	0	0	1	1
TOTAL	55	39	23	117

The mean score on the GHQ-12 was 13.8 (sd = 7.1, range 4-33). This was scored using the research scoring method of 0123.

Table 6.2

Summary of General Health Questionnaire (GHQ-12) Data

GHQ Item	Mean(SD)
1 (concentration)	1.48 (0.68)
2 (worry)	1.23 (0.95)
3 (useful)	1.36 (0.7)
4 (decision making)	1.26 (0.58)
5 (strain)	1.21 (0.92)
6 (difficulties)	0.89 (1.22)
7 (enjoyment)	1.67 (0.76)
8 (face problems)	1.15 (0.6)
9 (unhappy)	1.07 (1.0)
10 (lost confidence)	0.82 (0.98)
11 (worthless)	0.36 (0.72)
12 (happy)	1.18 (0.66)
Total	13.8 (7.1)

6.4.2 Distribution of Responses

The distribution of responses for each CCMM item within the measure was examined first according to tumour site (breast, lung or colorectal) and then with regard to disease status (localised, locoregional or metastatic). The structure used to facilitate visual inspection of these data (denoting the numbers of patients who responded for each possible option) is outlined at Table 6.3.

Table 6.3

Structure Used for Visual Inspection of Response Distribution

	Breast	Colorectal	Lung	Localised	Locoregional	Metastatic
Do Not Agree						
Agree Slightly						
Agree Moderately						
Agree Very Much						

The aim was to ensure that items were eliminated where one alternative had a very high or low endorsement rate and where retention of this item was not justified on account of potentially providing useful data . The initial threshold rates of endorsement were set at over 95% or less than 5%. No items were deleted on the basis of appearing to have skewed responses. There were six of the forty items where frequency of endorsement was less than 5%. These items were reviewed and a decision was taken to retain the items in each case on the basis that even though the overall frequency of endorsement was

lower, that the information that would be obtained from such an endorsement was regarded to have sufficient potential to be useful. An example of this would be the item ' I have lost control of my life because of cancer' where it was thought that the fact that 3% of respondents agreed very much with this statement may in itself be of clinical significance if this item were to be within the final measure.

Although these decisions made on the basis of response distributions for all responses to items, distributions were also visually examined according to primary cancer site and disease status in order that any items which might have been biased toward cancer or prognostic characteristics could be identified. These are reproduced within Appendices 15 and 16. Although visual inspection of some items might suggest that responses would themselves have different meaning according to whether someone had advanced disease (e.g. 'I keep thinking that my cancer might come back or might spread' or 'I think that I will be cured of my cancer') the percentage distribution of responses would suggest that some respondents where objectively the chance of cure is not high still endorse a high level of agreement that considering cancer means a cure for them (e.g. 26% of people with metastatic disease agreed very much that they would be cured of cancer). The extent to which the meaning that is experienced is congruent with reality, although an important consideration with regard to the wider issue of understanding acceptance, coping and adjustment, is secondary in terms of developing a measure that assesses the meaning. The potential for dissonance between situational meaning and reality exists not only with meaning items regarding advanced disease but can be appreciated too with items on other elements of cancer experience (e.g. 'Other people pity me

because I have cancer' may or may not be an unbiased perception of a respondents experiences with others).

It was especially important to produce a measure that assessed generic elements of what it meant to have cancer. Missing variable analysis was conducted on responses to the measure for the purpose of examining whether there were particular variables that were more likely to have missing data. There were no items that had a greater proportion of missing values.

6.4.3 Inter-Item Correlations

The aim to develop a homogeneous scale where each item assesses a different element of the same overall construct requires that the final scale will have items that are moderately correlated with each other (Streiner & Norman, 1995). Without this, there would be a loss of content validity and a greater degree of redundancy within the measure. In addition to these requirements for inter item relationships, each item should correlate with the total scale score. The Pearson correlations between the items within the CCMM were computed (N=111). The sample size is 111 as computations for correlating each item with every other only include cases where there are no missing data on any item within the scale. The resulting matrix of correlation coefficients was inspected for inter item correlations that were greater than 0.6 (see Table 6.4). Correlation coefficients of greater than 0.6 are generally regarded as being high.

Table 6.4

Items that Inter-correlate more than 0.6

Item Numbers	Item Content	Correlation
3,10	It is not fair that I developed cancer	0.65

	Cancer should not have happened to me	
18,4	My life has been shattered because of cancer I don't plan for the future because of my cancer	0.67
9,6	I think about my cancer all of the time I cannot escape reminders that I have cancer	0.63
18,7	My life has been shattered because of cancer My world has fallen apart because of cancer	0.67
18,8	My life has been shattered because of cancer Cancer interferes with living my life	0.61
15,28	I appreciate life more because of cancer Cancer has made me really focus on what matters in life	0.61
40,15	My life has more meaning because of cancer I appreciate life more because of cancer	0.63
27,29	I keep thinking my cancer might come back I wonder if my cancer has spread	0.65

On the basis of inspecting the inter item correlations it was decided that five items would be removed from the scale on the basis that they were highly inter-correlated. These are outlined in Table 6.5. Removal of these items meant that following examination of multicollinearity, there were 35 items remaining on the measure. Some items were inter-correlated with more than one item and were therefore chosen for removal before items that were shown to highly correlate with only one other item.

Table 6.5

Items Removed on the Basis of High Inter-Item Correlations

I cannot escape reminders that I have cancer
Cancer should not have happened to me
I appreciate life more because of cancer
My life has been shattered because of cancer
I keep thinking my cancer might come back

6.4.4 Item-Total Correlations

Scale homogeneity can be determined by computing item-total correlations. Each correlation coefficient is the correlation of an individual item with the total of the scale with that item removed. Items that have higher item-total correlations have more shared variance with what all of the other items have in common and add to the reliability of a test (Nunnally & Bernstein, 1994). The Pearson product moment correlation is generally regarded as the best coefficient to use for this purpose. Streiner and Norman (1995) suggest that the item-total correlation should be greater than 0.2 and that items below this value should be eliminated. Nunnally and Bernstein (1994) suggest that the threshold be set at 0.3. Item-total correlations were computed for the remaining 35 items. (See Table 6.6)

Table 6.6 Corrected Item-Total Correlations

Item	Corrected Item-total Correlation
1	0.27
2	0.39
3	0.48
4	0.39
5	0.26
7	0.57
8	0.38
9	0.51
11	0.46
12	0.12
13	-0.08
14	0.44
16	0.24
17	0.32
19	0.50
20	0.16
21	-0.15
22	-0.14
23	0.27
24	0.06
25	-0.01
26	0.23
28	0.32
29	0.39
30	0.38
31	0.46
32	0.07
33	0.14
34	0.14
35	0.25
36	0.30
37	0.25
38	0.16
39	0.33
40	0.33

On the basis of Nunally and Bernstein's recommendation that item-total correlations of greater than 0.3 be retained, 15 items were removed from the scale at this stage. These items are outlined in Table 6.7.

Table 6.7 Items Removed on the Basis of Item-Total Correlations of < 0.3

12. My faith will see me through having cancer
13. Cancer is not as bad as it is made out to be
16. Everything about cancer is bad news
20. I accept that I have had cancer
21. I think that I will be cured of my cancer
22. I have control over my cancer experiences
24. Some good things have come from my having had cancer
25. I am more fortunate than most people who have cancer
26. Other people do not understand what it is like to have cancer
32. There are worse things that could have happened to me than having cancer
33. I have no future because of cancer
34. Luck will determine what will happen to my cancer
35. Others I know with cancer have inspired me
37. I don't understand what is happening with my cancer care
38. Other people's reactions to my cancer give me hope

6.5 Conclusions

The data reported in the preceding sections relate to the need to carefully ensure that item content is both consistent with the aim of developing a generic measure (i.e. not one that contains items that are biased toward cancer sites or therapy regimes) and with the aim of maximising the internal validity of the scale. Visual inspection of item response distribution in accordance with tumour site and disease status has confirmed the relevance of each item to core meanings. Analysis of inter-item and item-total correlations resulted in the identification of a smaller subset of items for retention and upon which to base further analysis of the psychometric performance of these items.

6.6 Test-Retest Reliability

6.6.1 Introduction

The 20 items that remained in the scale were analysed to determine the extent of test retest reliability. The data for these 20 items were obtained from completion of the 40 item measure and not from a separate administration. The computation of correlations on nominal data is not appropriate. The kappa test (Cohen, 1960) can be used to test for the extent of agreement between two methods, raters or observers. Standard kappa takes no account of the size of disagreement between the two raters, only whether they agree or not. Data from an ordinal categorical scale is more suited to a weighted kappa test (Cohen, 1968). Absolute agreement between both raters (in this case patient response to a questionnaire item at two time points) is treated as it is within a standard kappa test. Disagreements are taken into account in a weighted kappa procedure, measured by the number of categories of difference between the two methods. This way partial credit is given to responses at second administration that would be regarded as disagreement within the computations used for other indices of reliability - for example, a patient who responded 'Agree Slightly' at time one and 'Agree Moderately' at time two would receive partial 'credit' for this as the second response was only one category away from their response at time 1. This was deemed to be a more suitable statistic for the computation of the level of agreement when the test was administered on two occasions.

In the case of the application of standard kappa to the determination of test retest reliability, it would provide an indication of the extent to which patient's responses at the second administration of the measure were identical to those given when the measure was first administered. The

weighted kappa procedure takes account of instances where a patient may have responded' Agree Slightly' at the first time of CCMM administration and 'Agree Moderately' at the second time. Table 6.8 outlines data from one item at both times of administration, with kappa and weighted kappa statistics.

6.6.2 Method

The Health Care International (HCI) facility at Clydebank in Glasgow had a contract with the Beatson Oncology Centre to provide radiotherapy. It was decided to recruit from this clinical area in preference to the other clinical areas that had been the focus of recruitment at prior stages in the development of the measure. This was chosen to facilitate recruitment as the service at HCI is provided within a defined space within the hospital (as opposed to the Beatson Oncology Centre where radiotherapy provision is housed with a larger supra-regional cancer centre that has several radiotherapy treatment rooms). Permission for this arrangement was sought and granted by the Clinical Director of the Beatson Oncology Centre. Patients that were attending for radiotherapy were chosen as they were all scheduled to attend once each day for a period of six weeks. This made it easier to follow up patients for the purposes of ensuring that they completed the questionnaire for the second time within a uniform time period. Patients were invited to participate when they attended for radiotherapy. They were asked if they would be willing to complete the measure again approximately three weeks after the first completion date and reminded that they could withdraw their consent at any time after the initial completion of the measure and that, as such, there was no obligation to complete the measure for the second time

6.6.3 Results

Twenty-six patients with breast cancer completed the measure on two occasions.. Patients received copies of the measure in the post approximately three days prior to the date that was three weeks following the date of initial completion. Patients handed the completed measure to the radiography staff at the Health Care International Radiotherapy Department or returned this by post to the University Department of Psychological Medicine. Although 26 patients completed the questionnaire on two occasions, precise dates of completion were only available for 15 patients. These patients completed the questionnaires an average of 18.3 days (range 16-21days) following the first completion. The fact that the other 11 patients returned their questionnaires by post indicates that they were completed within the desired three week time frame but the absence of date of completion information made it impossible to compute the time from first to second completion. Patients and clinicans were asked to indicate whether any significant event occurred between first and second completion of the measures. No such events were recorded.

Table 6.8

Weighted Kappa for Item 1 'My Cancer Philosophy is Live for Today'

Time 1	Time 2			
	D	AS	AM	AVM
Disagree (D)	2	0	0	0
Agree Slightly (AS)	1	2	1	0
Agree Moderately (AM)	0	0	3	2
Agree Very Much (AVM)	0	0	2	10

Weighted kappa = 0.8 (Conventional kappa = 0.6)

Table 6.9

Weighted Kappa and Correlation Coefficients for Items Remaining in Measure at this Stage in the Development Process

Item	Weighted Kappa	Correlation coefficient
My cancer philosophy is live for today	0.8	0.6
Cancer rules my life	0.8	0.3
It is not fair that I developed cancer	0.6	0.6
I don't plan for the future because of my cancer	0.2	0
Having cancer is a challenge to me	0.4	0
My world has fallen apart because of cancer	0.4	0.3
Cancer interferes with living my life	0.5	0.3
I think about my cancer all of the time	0.5	0.2
My thoughts about cancer are out of control	0.2	0
Cancer has changed every aspect of my life	0.2	0.1
Other people pity me because I have cancer	0.5	0.2
I am a completely different person because of my cancer	0.2	0.2
Cancer is a death sentence	0.4	0.4
Cancer has made me really focus on what matters in my life	0.5	0.5
I wonder if my cancer has spread	0.7	0.8
I must have done something wrong in my life to have developed cancer	0.3	0.3
Other peoples reactions to my cancer make me pessimistic	0.4	0.5
I have some control over the course of my cancer	0.3	0
I have lost control of my life because of cancer	1	1
My life has more meaning because of cancer	0.7	0.7

Six items were removed from the scale on the basis of having weighted kappa statistics of less than 0.4. This meant that there were 14 items remaining for the scale that was to be subjected to an exploratory principal components analysis. If decisions for removal had been made on the basis of correlation

coefficients then five more items would have been removed. These issues relating to the use of different indices of test retest reliability will be discussed at section 6.11.2

6.6.4 Conclusions

Although it would be expected that there would be changes in core meanings associated with cancer experiences in connection with personally salient events, the measure should not result in changes when there have been no such significant factors to account for this. It would be consistent with the way in which the construct had been operationalised if, for example, changes occurred on the measure between an administration that first occurred during the time following diagnosis and then again prior to the commencement of treatment (as we know that there is much for patients to contemplate and think about around this time). It would however, be less desirable if changes occurred when repeat administration was arranged for a group of patients at another stage in their cancer experience when there is known to be greater stability in emotion and psychosocial adjustment.

6.7 Principal Components Analysis (PCA)

The method used for the collection of data that will be subject to analysis and discussion in this section was that outlined at section 6.2. The specific goals of PCA are to reduce a large number of observed variables to a smaller number of components (Tabachnick & Fidell, 2001). Interpretation and naming of factors depend on the meaning of the particular combination of observed variables that correlate highly with each component. An exploratory PCA was performed to identify dimensions within the measure. The eigenvalues for the

first seven consecutive components were 4.5, 2.3, 1.04, 0.97, 0.83, 0.78 and 0.73. Using the eigenvalues greater than one criterion, three components were suggested for retention. Cattell's scree test was also examined to provide a further basis upon which to choose components to retain. This also suggested that a three-factor solution would be appropriate. The third component's eigenvalue was 1.04. It was decided to retain this component as it contributed to 7% of the variance.

The initial component solution was subjected to varimax rotation as the aim was to identify components of situational meaning that were relatively independent of one another. Varimax rotation was chosen in order to maximise distinctions among the components. Items were regarded as loading significantly if they achieved a value greater than or equal to 0.45. The results of PCA in terms of contributions to explained variance can be found at Table 6.10 and component loadings are presented within Table 6.11 Three factors explained a total of 56% of the total variance.

Oblique rotations allow factors to be correlated, compared with orthogonal rotations such as Varimax that keep them uncorrelated with one another. Inspection of an oblique rotation with these data suggested that there was only a borderline correlation between components and that the acceptance of the orthogonal rotation was justified. The rotated component matrix (denoting the correlation between variables and components) was inspected in order to ascertain whether the pattern of variable loadings were meaningful. The decisions regarding the labelling of components were taken with regard to the prevailing themes in current research into cognitive components of adjustment to cancer and other physical illnesses.

Items were inspected for the purpose of identifying possible underlying dimensions for responses. The first component consisted of four items that loaded highly on this component ('Other people pity me because I have cancer'; 'Cancer is a death sentence'; 'Other peoples reactions to my cancer make me pessimistic' and 'I have lost control of my life because of cancer') and with smaller loadings on components two and three. Two further items had significant loadings on the first component but also on the second component ('Cancer rules my life') and ('Cancer interferes with living my life').

Table 6.10

Eigenvalues, Percentage of Variance and Cumulative Percentages for Factors of the Core Cancer Meanings Measure

Component	Eigenvalue	% Variance	Cumulative %	% Explained
1	4.5	32.11	32.11	57.25
2	2.32	16.55	48.65	29.50
3	1.04	7.41	56.09	13.21

Table 6.11

Loadings for Components on Principal Components Analysis

	Meaning Co 1 Negative	Meaning Co 2 Search for	Meaning Co 3 Positive	Communality
My cancer philosophy is live for today	0.24	-0.25	**0.65**	0.54
Cancer rules my life	**0.68**	0.44	-0.12	0.66
It is not fair that I developed cancer	0.14	**0.65**	0.16	0.47
Having cancer is a challenge to me	<0.01	<0.01	**0.63**	0.4
My world has fallen apart because of cancer	0.28	**0.82**	<0.01	0.75
Cancer interferes with living my life	**0.54**	0.50	-0.14	0.56
I think about my cancer all of the time	0.50	**0.57**	<0.01	0.58
Other people pity me because I have cancer	**0.69**	<0.01	<0.01	0.49
Cancer is a death sentence	**0.63**	0.22	-0.13	0.47
Cancer has made me really focus on what matters in life	-0.28	0.28	**0.71**	0.66
I wonder if my cancer has spread	0.21	**0.60**	0.16	0.44
Other peoples reactions to my cancer make me pessimistic	**0.65**	0.18	0.22	0.5
I have lost control of my life because of cancer	**0.74**	0.24	-0.25	0.66
My life has more meaning because of cancer	-0.16	0.16	**0.79**	0.68

All items with higher loadings are related to negative interpretation of cancer experience with regard aspects of the self, relationships, cancer and interactions of these elements. Component one was labelled 'Negative Meaning'. The first dimension of Park and Folkman's (1997) proposed model of situational meaning outlined earlier can be identified within this first component. Their dimension was named 'appraisal of meaning' and contains elements of this 'Negative Meaning' scale. The content of this first component is in keeping with the observation that interpretations are often related to the way in which personal beliefs and commitments are affected by

illness (Folkman & Stein, 1996). The potential significance of the loading of two component one items on the second component will be considered when the items with highest loadings on component two have been outlined.

Three items loaded highly on the second component. These were 'It is not fair that I developed cancer'; 'My world has fallen apart because of cancer' and 'I wonder if my cancer has spread'. A fourth item, although loading highly on component two, also had a high loading on component one 'I think about my cancer all of the time'. The items that loaded significantly on only the second component are all thematically related to cognitive aspects relating to the products of information processing as a result of patients trying to make sense of their experiences. Patients may experience thoughts about whether cancer represents an ongoing threat, a sense of injustice and some find it difficult to accommodate their cancer experiences within existing mental frameworks.

It is proposed that the underlying dimension here relates to the thinking processes relating to the personal significance of cancer occurrence and recurrence and was therefore labelled 'Search for Meaning'. The underlying issues of rumination (Martin *et al.* 1993); causal attributions (Smith *et al.* 1993); shattered world views in response to live events (Epstein, 1991) and thoughts about justice in relation to negative life events (Tomaka & Blascovich, 1994) are all recognised elements of this cognitive process of searching for meaning.

The three items that have high loadings on components 1 and 2 are elements of situational meaning that relate both to the individual negative

interpretations that patients have but also reflect the process of searching to make sense of cancer occurrence, likelihood of disease spread and the personal implications of the disease. All the items with dual loadings on a 'Negative Meaning' component and 'Search for Meaning' component seem to relate to perceived degree of illness intrusiveness. This pattern of component loadings is consistent with the wider theoretical context that such negative interpretations in particular are likely to become associated with questions regarding cancer significance and shattered assumptions.

Four items loaded highly on the third component. These were 'My cancer philosophy is live for today'; 'Having cancer is a challenge to me', 'Cancer has made me really focus on what matters in life' and 'My life has more meaning because of cancer'. This component is clearly linked with issues relating to perceived benefits and consequences that can sometimes arise in adverse life circumstances (Thornton, 2002).

6.8 Internal Consistency

The internal consistency of the resulting 14-item Core Cancer Meanings Measure was calculated using Cronbach's alpha. Alpha for the remaining 14 items was 0.8. Deletion of individual items did not result in a drop in alpha below 0.74, indicating that all items contributed equally to the consistency of the scale. Corrected item-total correlations (the correlation of each item with the total score of the remaining 13 items) ranged from 0.14 to 0.62. Cronbach's alpha was computed for each of the component scales - these values were acceptable at component 1 (alpha = 0.83), component 2 (alpha = 0.7) and component 3 (alpha = 0.66).

Cronbach's alpha is dependent upon the number of items on the scale and also the magnitude of correlations among the items. The value of coefficient alpha is relevant as the magnitude of this determines the degree to which items are asking the same question in different ways. If it is too high then the scope of the scale will be too narrow. Streiner and Norman (1995) suggest that this should be greater than 0.7 and less than 0.9. The Pearson product-moment correlations among the total scores on components were 0.54 (components 1 and 2) and 0.14 (components 2 and 3), 0.01 (components 1 and 3).

Examination of the distribution of responses revealed that 13 items had values of skewness and kurtosis which suggested a distribution which was not skewed, though the item 'I have lost control of my life because of cancer' was skewed (skewness = 2.48, kurtosis = 5.18).

6.9 Final Core Cancer Meanings Measure Items

Given the confusion that can sometimes exist between meaning, coping and adjustment (see section 2.3.6),it is hardly surprising that it may seem that there a many overlaps with measures such as the Mental Adjustment to Cancer Scale and the CCMM. It is inevitable that there will be some overlap in content area in that the construct that is assessed by these measures (ie coping or adjustment) are related to the meanings ascribed to cancer experience. Given that the MAC is one of the most commonly used measures within psychosocial oncology, the similarities and differences between the MAC and CCMM will now be considered

Eight of the fourteen items from the final version of the CCCM have no similar items on the Mental Adjustment to Cancer Scale. These are 'Cancer rules my life'; 'It is not fair that I developed cancer'; ' My world has fallen apart because of cancer'; 'I think about my cancer all of the time'; 'Other people pity me because I have cancer'; 'Cancer is a death sentence'; 'Other peoples reactions to my cancer make me pessimistic' and 'My life has more meaning because of cancer'. Three of the four items on 'positive meaning' subscale of the CCMM ('My cancer philosophy is live for today'; 'Having cancer is a challenge to me' and 'Cancer has made me really focus on what matters in my life) are similar in theme to some which have been described among those that load on the 'fighting spirit' or 'positive re-appraisal' subscales of the MAC. It is increasingly being recognised that positive reappraisal coping might constitute a separate dimension of coping and here one would expect a measure of meaning and one of coping to overlap, though this does require closer study in the future not only in terms of the relationship of these two measures but in order to better appreciate the boundaries of the concept of meaning and that of coping. Two of the six items on the negative meaning subscale of the CCMM ('Cancer interferes with living my life' and 'I have lost control of my life because of cancer') are similar in theme to MAC items, though they have not been consistently shown to have similar subscale affiliations in the various studies that have examined MAC structure. One from the four on the 'Search for Meaning' subscale ('I wonder if my cancer has spread') is thematically linked to themes reflected in MAC items.

There are some important differences between the CCMM and the MAC. Particular effort has been made in wording the CCMM items to ensure that the focus on meaning with regard to cancer is clear for each item. Although it is

likely that respondents to the MAC understand that each item relates to cancer (as stated in the instructions for administration), there are still items where the focus of items could be open to misinterpretation (e.g. 'I try to keep a sense of humour about it', 'I feel fatalistic about it'). The CCMM is a cognitive measure and al items are clearly cognitions. The MAC, reflecting its purpose as a measure of coping, contains items with emotional ('I suffer great anxiety about it'; 'I feel very angry about what has happened to me'). Cognitive ('I firmly believe that I will get better') and behavioural ('I have been doing things that I believe will improve my health e.g. changed my diet') dimensions within response stems. The MAC invites respondents to endorse the degree to which each item applies to them, in contrast to the emphasis on the CCMM on level of agreement with item. It is not clear on what basis respondents to the CCMM might relate an item as having greater applicability to themselves - this could be on the basis of frequency or level of conviction.

6.10 Relationship of CCMM Items to General Health Questionnaire Items

Table 6.12 outlines the relationship between CCMM subscales and General Health Questionnaire responses. In keeping with research that has shown a relationship between both negative meaning, search for meaning and psychological distress, the corresponding CCMM subscales are statistically significantly positively correlated with the GHQ Total Score. Although positive meaning might not correlate with the presence or absence of psychological distress it is possible that the use of positive items within the GHQ-30 (see

Huppert and Whittington, 2003) might demonstrate correlations within the CCMM positive meaning subscale.

Table 6.12 Correlations Between CCMM subscales and GHQ-12 Total Score General Health Questionnaire Score

CCMM Negative Meaning	0.56 ($p<0.01$)
CCMM Search for Meaning	0.51 ($p<0.01$)
CCMM Positive Meaning	-0.10 (NS)

6.11 Discussion

6.11.1 Approach Taken to Item Selection

The phases that were followed in the selection of items for the new measure were implemented in accordance with the guidance provided by Streiner and Norman (1995). They suggest that frequency of endorsement and discrimination are considered first. The frequencies of endorsement for each of the CCMM items were calculated.. The frequency of endorsement was examined with respect to the primary site of cancer and also the disease status of the participants. This was done because of the need to ensure that the measure assessed an element of situational meaning that was sufficiently applicable across all tumour types to be included within the measure. The issue of homogeneity of the items was of central importance to scale development and this was why inter item correlation and item-total correlations were both chosen as the next indices to be used for the determination of item selection. Removing items on the basis of multicollinearity was important in view of the later intention to subject retained items to principal components analysis. If these issues had not been addressed then there would have been a greater risk that the eventual scale

would have ended up assessing more than one construct. In keeping with the aim of ensuring that the item selection process was undertaken to maximise the chance of producing a measure of situational meaning, it was decided to analyse the performance of the items when re-administered following a period of time.

6.11.2 Test Retest Reliability

There has been much debate about what is the most appropriate index of reliability to determine the performance of a measurement at two points in time. The most commonly used approaches are the Pearson correlation coefficient, Cohen's kappa (Cohen, 1960) and a method outlined by Bland and Altman (1986) that relies on graphical representation of data and computation of a repeatability coefficient. Bland and Altman (1986) suggest that the use of correlation to assess agreement between two methods of clinical measurement is misleading. Streiner and Norman (1995) disagree with the concerns expressed by Bland and Altman (1986) over conventional assessments of reliability but agree that Pearson is inappropriate by virtue of being overly liberal. They have suggested that the intraclass correlation coefficient is the statistic of choice for the determination of test retest reliability. Correlation coefficients are inappropriate for analysis of data on a categorical scale of measurement. Correlations are measures of association and not measures of agreement, the main focus of consideration here. Although these two concepts are linked they are not the same. Computation of a kappa statistic is better suited as an index of agreement for responses from repeat administration of the CCMM , given that it produces data on a categorical scale (Dunn, 1989).

Wide variations can occur when reliability is estimated with different statistics (Hunt, 1986). In this study the view was taken that an exact correspondence from responses from one administration to the next was not to be the sole determinant of agreement, but that agreement would be conceptualised as exact agreement or no more than one response category of a difference for responses at each administration of that item within the measure. This way weighted kappa provided for what is known as scaled disagreement where partial credit is given for some kinds of disagreements (Goodwin *et al.* 1991).

Pearson correlation coefficients measure the presence of a linear relationship with the data and, as illustrated in Table 6.9 provide different figures (as would be expected given the emphasis on association and the failure to take account of scaled disagreement). The calculation of Pearson and weighted kappa data has demonstrated how important it is to use the appropriate statistic to make judgements on the performance of items with repeat administration and that although they may be viewed as equivalent to guage reliability, they are not and there is no inherent statistical reason why they should provide equivalent results (McColl, personal communcation).

Test retest reliability data were computed with a sample of women with breast cancer who were all attending for radiotherapy. In view of the preliminary nature of this work to develop the CCMM this choice of sample to compute test retest data was taken intentionally in view of the likely stability of general physical and mental state. Future work will need to determine the test retest reliability of this measure when applied with cancer types and

treatment regimes where there are ongoing changes in wellbeing and physical health status over such a period of three weeks.

6.11.3 Principal Component Structure and Interpretation of Item Content

Principal components analysis is often used as an aid to conceptualising the inter-relationships between a number of variables in a concise manner. This method is useful to identify conceptual dimensions that can be examined in future work. Item analysis is sometimes used as a technique for the determination of the content of a psychological assessment measure. Within approaches that use item analysis, decisions are made on the basis of item-total correlations and response distribution. There are a number of important issues that need to be taken into account in considering the processes and procedures that relate to principal components analysis. These relate to the type of analysis that should be undertaken (exploratory or confirmatory); the sample size; the type of rotation and the rotational method that are chosen and the number and nature of factors within the resultant structure.

An exploratory factor analysis was chosen in preference to a confirmatory factor analysis for two main reasons. First, that theoretical work on situational meaning was not considered to be sufficiently well developed to benefit from a confirmatory analysis at the point at which this work was being planned. Although Park and Folkman (1997) have outlined what they believe to be the components of situational meaning, their account is mostly a guiding model. Second, it was important to be able to describe and summarise relationships between items on a new measure of situational meaning and

exploratory analysis is better suited to the initial stages in the evolution of a new self-report measure.

Kline (1994) suggests that some of the estimates that have been made about the required sample sizes for the completion of factor analytic procedures are pessimistic. He suggests that samples of 100 are 'quite sufficient' (p. 73) when data has a clear factor structure. Much has been written about the adequacy of sample sizes with various authors recommending a range of values and heuristics to determine the adequacy of sample sizes for principal components analysis. Although Tabachnick and Fidell (2001) suggest that it is 'comforting' to have at least 300 cases and Comrey and Lee (1992) refer to samples of 100 as 'poor' there has been research focused upon the effect of various sample sizes on the factor solutions. Arrindell and van der Ende (1985) have suggested that it is not the subject to variable ratio that is important but that the subject to factor ratio that should be considered. They suggest that this should be more than 20:1. In the PCA on CCMM items the subject to factor ratio was well in excess of this at 40:1. Arrindell and van der Ende (1985) also reported that changes in subject to variable ratios made little difference to the stability of factor solutions and those factors with four or more loadings of greater than 0.6 are reliable regardless of sample size. McCallum *et al.* (1999) concluded that communalities in the 0.5 range with a sample size in the region of 100 to 200 is adequate when there are few factors each with a relatively small number of variables. The component matrix for CCMM items outlines a few distinct factors with strong and reliable correlations, which according to Tabachnick and Fidell (2001) is acceptable for a smaller sample.

Tabachnik and Fidel (2001) suggest that "decisions about numbers of factors and rotational scheme are based on pragmatic rather than theoretical criteria" (p.586). In order to appreciate the decisions that were made regarding the rotational scheme it is important to outline what is meant by the term 'simple structure'. This term, first used by Thurstone (1947), relates to the presence of several variables that correlate highly with each factor and that each variable correlates with one factor. Given that poor rotation is often a cause of failing to reach simple structure and that varimax is the most efficient procedure for attaining simple structure (Kline, 1994), varimax rotation was computed initially. Nunally and Bernstein (1994) suggest that varimax rotation captures the meaning of simple structure very well. The aim of analysis was to identify relatively independent clusters within the target construct and as such, an orthogonal solution was ideal.

The other possibility in terms of rotation would have been to carry out an oblique rotation. Kline (1994) suggested that where an orthogonal simple structure rotation is desired that varimax rotation should be used. Orthogonal rotations are preferred when it is believed that there are independent underlying processes within item responses to be rotated. With the analysis reported here the view was taken that although one would expect components of situational meaning to be related thematically the aim was to find independent dimensions of situational meaning. Nunnally and Bernstein (1994) suggest that orthogonal rotations usually lead to essentially the same major groupings as oblique rotations and that a varimax solution will "usually do as well as any oblique rotation" and that there is the added advantage of simplification that is associated with orthogonality. Field (2000) suggests that running both orthogonal and oblique rotations is an approach that can be

adopted. Pedhazar and Schmelkin (1991) suggest that if an oblique rotation demonstrates a negligible correlation between extracted factors then it reasonable to use the orthogonally rotated solution.

Jolliffe (1986) has suggested that Kaiser's (1960) criterion for the retention of components with eigenvalues greater than 1 is overly strict and that items with eigenvalues greater than 0.7 should be retained. Field (2000) has suggested that Kaiser criterion is accurate when the number of variables is less than 30 and/or the average communality is greater than or equal to 0.6 (as it is in the case of the PCA that was reported here). Although researchers often report component loadings with a value of 0.3 or more to be important in interpreting the loadings of items on components, the significance that is attached to loading values should be dependent upon the sample size. Stevens (1992) suggests that for a sample size of 100 the loading should be greater than 0.512. These values are based on a two tailed alpha value of 0.01. All component loadings for CCMM items were above this value.

The dimensions that were proposed as unifying the groups of variables that loaded upon each component were formulated with regard to existing knowledge and literature. This has been referred to as "...a process that involves art as well as science" (p.625) (Nunally and Bernstein, 1994). The components broadly reflected the elements of situational meaning that were hypothesised as part of the model outlined by Park and Folkman (1997). The CCMM is therefore likely to prove to be a useful addition to those measures that are already available to investigate global meaning (this theme will be further developed in Chapter 7). The measure also reflects findings from work that has examined the need to encompass both positive and negative

dimensions of meaning. This is both in terms of including items that cover positive and negative content and also ensuring that the item content addresses elements of positive meaning such as benefit finding, positive reappraisal coping and posttraumatic growth (Sears *et al.* 2003). It has been suggested that positive and negative effects following traumatic experiences can exist within the same person (Aldwin, 1994). Here the inclusion of items with positive and negative dimensions is in keeping with this observation.

The shared variance between components 1 and 2 (29%) is consistent with what is know about psychological correlates of the search for meaning that occurs following exposure to a traumatic event.

Mohr *et al.* (1999) and Katz *et al.* (2001) have reported the results of a factor analysis of responses of a group of people with cancer or lupus (Mohr *et al.* 1999) and multiple sclerosis (Katz *et al.* 2001) on a questionnaire designed to assess the psychosocial effects of chronic illness. Both studies identified three factors among the response of patients to a questionnaire that was originally developed for the Mohr *et al.* (1999) study. These were labeled 'demoralisation', 'benefit finding' and 'relationship deterioration'. The content of the items on the third component included some of the components of positive meaning that have been outlined in the literature. Thompson (1985) outlined these as finding benefits, making social comparison, imagining worse situations, forgetting the negative and redefining. The potential that exists for personal growth to occur following a cancer diagnosis (Taylor *et al.* 1984) and recurrence of cancer (Mahon *et al.* 1990), the adoption of a mind set that emphasises living in the moment (Ersek *et al.* 1997) or to 'live each day to the fullest' (Mahon & Casperson, 1997) have also

been outlined. Tedeschi and Calhoun (1996) found that all participants in one of their studies reported negative effects of their experience of trauma and that 60% of them also reported positive effects. They suggest that the perception of benefits does not imply the denial of difficulties or problems. Ersek *et al.* (1997) found that their sample of women with ovarian cancer reported both positive and negative influences on their quality of life.

6.12 Conclusions

This chapter has described a series of iterative stages that have been applied to data collected from responses on the CCMM. These stages generated data upon which decisions about item retention were made, according to accepted criteria for scale development. PCA resulted in a three-component solution that approximated simple structure and accounted for fifty six per cent of variance. These components were labelled 'Negative Meaning', 'Search for Meaning' and 'Positive Meaning'. It was possible to appreciate elements of the model of situational and global meaning proposed by Park and Folkman (1997) within the component structure. The first component of the CCMM ('Negative Meaning') linked with the element of their model relating to interpretations of the personal significance between the person and the environment (in this case regarding cancer). The second CCMM component ('Search for Meaning') is a reflection of their emphasis on the search for meaning that takes place. The third element that they propose regarding situational meaning relates the outcome of an interaction with global meaning content is clearly evidence within the content of the third CCMM component ('Positive Meaning'). The resultant measure has very good internal consistency. The following section Chapters will discuss future opportunities

for research with the measure and on possible future applications of the CCMM and its conceptual basis.

SECTION THREE DISCUSSION

The CCMM has been developed through a series of iterative stages. Data from qualitative interviews were inspected and thematically analysed to develop a pool of items relating to the target construct. Common themes within the thoughts and beliefs of a heterogeneous sample of people who have had cancer were outlined. These were incorporated into an initial version of the CCMM. Items were then revised or removed on the basis of feedback from a panel of expert reviewers and patients during a field-testing phase.

A forty item version of the measure was administered to a sample of 141 patients with breast, colorectal or lung cancer and the performance of individual CCMM items was examined in relation to inter item correlation, item-total correlation and test retest reliability. Fourteen items were retained for a final version of the CCMM and the component structure was analysed using principal components analysis with varimax rotation. This resulted in three components that accounted for a total of 56% of the variance. These were labelled 'Negative Meaning' (6 items, 57% of explained variance), 'Search for Meaning' (4 items, 29% of explained variance) and 'Positive Meaning (4 items, 13% of explained variance).

The opportunities for further research to examine construct, criterion and discriminant validity and to examine the component structure of the CCMM will be outlined in Chapter 7. The opportunities for application in clinical settings and the contribution of the CCMM to better understanding the concept of situational meaning will be examined in the final Chapter.

Chapter 7 Future Research Possibilities Arising From the Development of the Core Cancer Meanings Measure

This Chapter will outline possibilities for further research. In section 2, brief discussion sections were specific to the content of Chapters 4, 5 and 6. Here and in the following Chapter more general issues raised by this research will be addressed. This Chapter will consider specific developments relating to the CCMM and discuss the need for further research on its underlying constructs.

7.1 Overview of the Development of the Core Cancer Meanings Measure

The overall significance of this work should be considered in the context of its strengths and limitations. The following observations will provide a helpful starting point in considering how further elements of scale development might be addressed in future work.

Scale development progressed through the application of a series of iterative stages. The CCMM was developed following inspection of themes within a qualitative framework (to generate an item pool as opposed to embarking upon qualitative analysis). Items were further refined to take account of expert and patient views on early versions of the CCMM and concluding with a range of quantitative psychometric analyses. The considerable time and effort thatwas invested in the interviewing of patients for the purpose of generating themes for the pool of items resulted in a strong level of familiarity with what patients had been experiencing. This assisted the process of wording items andwas one of the factors that contributed to the good evidence for face validity that was generated during the field-testing phase. The rigorous approach that has been adopted for analysis, refinement of item content and the retention of items has resulted in a measure that has good psychometric properties, according to accepted standards. The demonstration of

thisvalidity has not been achieved at the expense of the relevance of item content or practical utility, a theme that will be more fully explored in the next Chapter. The work that has been reported in this thesis has included elements of scale development that are not seen in some other studies, particularly relating to the time taken at that stage of developing the initial item pool and the decision to include a field testing phase. This allowed patients to elaborate on the ways in which they had responded to the measure and provided an invaluable source of information for the later stages of interpreting the content of item subscales following principal components analysis.

Although a large number of items have been removed from the initial pool of items (47 in total), the themes within these items are reflected within the items that have been retained. If this had not been the case then this would have represented a significant threat to the validity of the CCMM. All of the analyses on the psychometric performance of individual CCMM items were conducted using data obtained from a sample of patients that had completed the 40 item measure, rather than ensuring that each iterative step in scale development was conducted with a series of newly recruited patients. This would have meant collecting data after each successive revision to the measure. If the alternative approach were applied then data for each iterative step would have been collected using versions of the CCMM with a different total number of items. This approach would not have been practical within the time available. The data used in the PCA were also generated from patient responses to the 14 CCMM items that remained following the application of the criteria on item retention. Given the acknowledgement both of the preliminary and developmental nature of this work on the CCMM

and that outcomes reported here need to be subjected to further investigation and validation, it is argued that this approach to generating data to assist decisions on item retention was justified.

It is possible that the responses that were made on an item embedded within a 40 item measure would not be the same to those that would have been made had the item been embedded within a measure that had only 20 or 14 items in total. The assumption here that was made in proceeding with the PCA was that respondents would have endorsed the items in the same manner no matter what order each one appeared within the questionnaire and that the total number of items would not have mattered. This is an interesting empirical question and one that could be tested out in the future. Administering parallel forms of a measure where the different forms have a differing number of total items and in which the position of each item within the overall item set is varied would provide data that could be examined to determine the impact on response profiles and component structures.

It is possible that the decision to adopt the response dimensions within the Metacognitions Questionnaire (with only one disagree option) may have resulted in questionnaire responses that were significantly skewed. Although examination of the distribution of responses revealed that the majority of items did not show significant skewness it is still possible that a constriction in the range of possible scores might occur - a separate and distinct consideration from the psychometrics of skewed distributions.

The development of this scale is also somewhat constrained by the fact that initial inspection in item content could leave some with the impression that

this scale is simply another to assess cancer related coping and/or adjustment. This limitation will only be addressed when the CCMM is examined in further work and the precise boundaries between these concepts and the peformance of the CCMM in comparison to the Mental Adjustment to Cancer Scale and Cancer Coping Questionnaire is examined more closely.

7.2 Future Research and Development of the Core Cancer Meanings Measure

This work has resulted in the development of a short measure that has good properties with regard to psychometric performance. CCMM items are reflective of themes that can be appreciated within the common concerns experienced by people with cancer attending clinics and hospitals. There is a need to further develop and examine the performance of the CCMM. Streiner and Norman (1995) suggest that as validation of an assessment measure is a process of hypothesis testing it is somewhat artificial to divide the discussion of validity according to traditional divisions such as construct and criterion related validity. For ease of presentation the following sections will be divided according to these widely used terms and specific hypotheses will be outlined within them.

7.2.1 Construct Validation

Construct validation will require that the CCMM demonstrate the expected pattern of relationships between test scores and other measures. The relationships among scores on components of the overall scale also need to be examined on the basis of what would be expected in light of what is known about the constructs that they assess. Considering the CCMM, the MAC and the

CCQ. one would expect there to be commonly shared variance but that, if as this work is suggesting, there are aspects of situational meaning that sit independently of adjustment and coping then multivariate analyses of data from these scales would demonstrate this. Construct boundaries in the areas of distress, spirituality and global meaning could also be usefully examined as the CCM M evolves as a research instrument.

The initial data reported here suggest that, although this is a short measure, it does not suffer from construct under-representation. This judgment is based on visual inspection and examination of the content that has been chosen for inclusion in the final measure. The efforts to ensure construct relevance at early stages in scale development have been important. With any new assessment of a psychological construct, there is always an issue with regard to the extent to which responses might be affected by method variance. No matter what patients are asked about with regard to their psychological experiences, a proportion of the variability in response will relate to the fact that this is being assessed by a self-report measure. Self-report measures of cognition are also often confounded by trait variables such as high trait anxiety (Deary *et al.* 1997) Research to examine the construct validity of the CCMM should take account of the potentially confounding nature of the method being used for assessment and dispositional factors such as high trait anxiety. It is possible that much of the information that is obtained from the examination of the responses of patients to the negative meaning subscale could be accounted for by high trait anxiety or that the information within the positive meaning (PM) subscale may be a proxy for trait optimism. A future study to determine the contribution of this and other trait variables to overall CCMM responses will be essential.

The internal structure of any new assessment measure should be consistent with what is known about the internal structure of the construct domain. Current literature suggests that positive meaning, negative meaning and the process of searching for meaning are each important elements of the way in which patients interpret their experiences (Park & Folkman, 1997; Thornton, 2002). There is not yet a consensus within the literature on how these dimensions might combine or relate to each other. The fact that the final version of the CCMM includes these elements is therefore consistent with current knowledge, though it is hoped that as other studies examine these issues that subscale scores could be examined in light of new understanding of meaning dimensions. An improved understanding of the inter-relationship of these dimensions will hopefully develop as more research data, including from the future application of the CCMM, are available.

The greater emphasis that exists within the wider literature on global meaning and the existence and application of some global meaning measures in cancer makes it possible to make some predictions about links between global and situational meaning in cancer. Patients with more negative global meaning structures (such as those that might be identified using the Life Attitude Profile) would be expected to have different profiles on the CCMM. This expectation is based on the proposed interactions outlined in Park and Folkman's (1997) model referred to earlier. Patients with a more positive score on the Life Attitude Profile would be likely to have higher scores on the positive meaning subscale of the CCMM.

Johnson-Vickberg *et al.* (2000) examined the links between high and low global meaning as a potentially protective factor for the experience of intrusive thoughts and psychological distress. In their study, global meaning appeared to moderate the relationship between intrusive thoughts and distress. Patients with low meaning (operationalised in the Johnson-Vickberg study as low scores on the Personal Meaning Index of the Life Attitude Profile) would be more likely to show higher scores on the search for meaning scale of the CCMM. Patients with lower overall global meaning would be more likely to be concerned about issues such as a sense of injustice, spend time thinking about their cancer, whether it has spread and that this would be reflected in a higher score on the 'Search for Meaning' (SFM) subscale of CCMM. Scores on the SFM subscale should therefore also correlate with the presence of intrusive thoughts about cancer, something that could be examined by considering the relationship of the subscales of the CCMM with the Impact of Events Scale (Sundin & Horowitz, 2002). Patients who report a greater number of sources of meaning (as measured on the Sources of Meaning Profile) should score more highly on the positive meaning (PM) subscale of the CCMM. A patient with a higher SFM score may be more likely to report problems in decision making (due to their greater propensity to have to spend time making sense of their experiences and preoccupations regarding injustice).

Although this work on the development of the CCMM has been carried out with a sample with a range of cancers, it will be important to begin to examine the performance of the measure with a wider range of cancer types. The work reported here has aimed to produce a measure that assesses generic themes in thoughts about cancer and it is hypothesised that this will be evident when it is used with people who have a range of cancers. It will be important to

ensure that further work to examine the component structuredoes so in a manner that enables CCMM performance to be evaluated according to tumour type, prognostic grouping and treatment modality. . The three components that were identified should be present within situational meanings reported by people with other cancers. When research with homogeneous samples is not possible, research should aim to determine that there are not systematic differences in responses according to tumour type or disease status (until such times that more data is accumulated to support the assertion of a core profile across tumour types).

Messick (1995) has suggested that validity is determined not only by the items that comprise the measure but also related to the context of the assessment and the person that is being assessed. Work could be undertaken to understand how responses vary in accordance to assessment context. Situational meaning may differ in accordance with the setting in which patients are asked to consider their thoughts (e.g., home versus out patient setting) and in terms of the person who is asking them to complete the measure (e.g., medical practitioner versus nurse specialist). At present the CCMM is validated for use in a research setting. Profiles and responses could also be different when the measure is administered within the context of clinical care and by a clinician that is actively involved in their ongoing medical, nursing or psychological care.

Research that has examined the impact of unexpected recurrence has outlined how a recurrence that is unexpected has a greater impact on distress than one where there was a greater degree of awareness of the possibility (Cella *et al.* 1990). A patient who experiences a recurrence (or indeed any

other unexpected cancer related event) may have a lower likelihood of experiencing severe distress according to the constellation of situational meanings that they experience prior to the confirmation of the recurrence. This could be evaluated in a longitudinal design that examined the significance of early profiles on the CCMM with later response to unexpected cancer related events. Related to this is that the SFM component would be more evident for someone that described an event as unexpected than someone who expected the event and perhaps had less need to 'make sense'. Performance on the CCMM could be compared with performance on tasks of cognitive and information processing. Patients with higher scores on the PM subscale for example would be expected to demonstrate attentional biases toward positive meaning cues that would not be present among those with lower scores on this subscale. Meaning profiles could also be relevant to enhancing understanding of decision making and decision making processes. The dependent variable in such work would be something other than responses on other self report measures and as such would be free from any confounding influence of method variance.

7.2.2 Criterion Related Validation

Work to examine criterion related validity could examine concurrent validity and predictive validity. Concurrent validity data could be generated by examining performance of the measure on performance based measures that are collected at the same time as the target measure. There are few measures against which the CCMM could be compared. Some researchers have examined elements of meaning by relying upon single item measures (Davis *et al.* 1998), though these are unlikely to provide valid assessments of the underlying construct. The main criterion measures that could form the focus

of comparison with the CCMM are the Illness Cognition Questionnaire (ICQ), Constructed Meaning Scale and the measure that was used by Mohr *et al.* (2001) in his work on meaning in multiple sclerosis. Scores on the PM scale of the CCMM should be correlated with the 'perceived benefits' subscale of the Illness Cognitions Questionnaire and the 'negative meaning' subscale with the 'Helplessness' scale of the ICQ.

In considering the relationship of other measures of meaning it will be important to consider the decisions that have been made about the naming of the items within each subscale. An example of this relates to the ICQ. Initial inspection of the subscale names of this measure might lead to the conclusion that the subscale that is referred to as 'Acceptance' would be suitable for comparison within a concurrent validity paradigm with the 'SFM' subscale. The assumption here would be that patients with greater acceptance would have less need to 'search for meaning'. However, closer inspection of the items on the 'Acceptance' scale of the ICQ suggest that most of these relate to coping self efficacy (e.g., 'I can handle the problems related to my illness', 'I have learned to live with my illness', 'I think that I can handle the problems related to my illness, even if my illness gets worse' and' I can cope effectively with my illness'). In addition to sounding this note of caution about relying solely on subscale labels to make predictions to inform validity research, it underscores the importance in considering the labelling of the CCMM subscales that was referred to earlier. Convergent validity is a term used to refer to the extent to which scores on the target measure correlate with scores on measures of the same construct (not necessarily administered simultaneously). Some future studies to examine the CCMM and other assessments of meaning would provide data for both indices of validity at one

in the same time. Although the MAC Scale is generally believed to be a measure of coping, the thematic links with just under half of the CCMM items and the emerging literature on meaning making coping suggest that the performance of the CCMM and MAC need to be closely examined. It is entirely consistent with emerging theory of meaning making coping (Folkman and Moskowitz, 2004) that the positive meaning subscale of the CCMM should demonstrate some overlap with the MAC (though as it is being argued that they do not measure the same concept there should be differences in the extent to which each captures a patient who actively uses meaning making coping (more likely to be picked up by the MAC) than someone where that comprises part of the meaning of cancer to them, but is not necessarily a part of their individual coping repertoire when confronted with cancer related stressors.

Predictive validity is the extent to which scores on a target measure can be used to predict an individual's score on performance collected some time after the target measure. There are some interesting hypotheses that could be examined with regard to the predictive validity of the CCMM, focused specifically on an examination of the extent to which higher scores on particular subscales might indicate different response patterns later. This is of course also related to construct validation and illustrates how data can simultaneously provide evidence for more than one form of validity. This can be seen with the previously stated example of how someone with higher scores on the PM subscale might be more likely to have different psychological responses to subsequent cancer related events than someone with lower scores on this dimension. Indeed, White and Black (2003) found that the global meaning construct of sense of coherence was related to the presence

of fears of recurrence, outlining how here positive global meaning can influence specific cancer related thoughts and emotions. Data on predictive validity could be examined by linking scores on the PM subscale with expected reactions to future events.

One might expect to see a different pattern of daytime activity in someone with a higher PM score than someone with a lower PM score. Although this potential relationship would also generate data to support construct validity, predictive validity could be established by observing the pattern on the CCMM and type and nature of activity in the subsequent weeks. Examining the relationship of the CCMM to this and other behavioural factors would also minimise the contribution of method variance. Predictions that relate to expected performance on related measures could be developed. Patients that endorse responses consistent with their life having more meaning, a philosophy of living for the day and a greater focus on what they believe matters in their life (ie. high PM scale score) would be expected to be more likely to cope using meaning making coping than a patient with lower scores on the PM scale. Patients with greater negative meaning scale scores should have different coping profiles than patients with low negative meaning scores.

Work on predictive validity could work towards identifying situational meaning profiles that are associated with more positive psychological and social outcomes. This is particularly likely to be an outcome of work that examines the performance of patients on this measure within a longitudinal study. This could result in clinical observations that may assist with supportive care recommendations and outlines the importance of using this measure to

facilitate observational work, separate from very specific attempts to generate psychometric performance data.

7.2.3 Discriminant Validation

Discriminant validity is the extent to which scores on a measure are unrelated to scores on measures assessing other theoretically unrelated constructs. Within psychosocial oncology there are so many constructs that overlap it would be hard to find one where meaning should not have some relationship. Predictions could be made about degree of overlap for these and those where overlap is not expected (e.g. between core cancer meaning and sexual self schema) could be examined. Sensitivity and specificity of responses on the CCMM could be examined with regard to the presence of clinically significant distress. Patient profiles on CCMM subscales such as 'high search for meaning and low positive meaning' vs. 'low search for meaning and low positive meaning' could be examined. Streiner and Norman (1995) refer to this form of validation study as validation by extreme groups. The overlap between components 1 and 2 could limit their discriminant validity. Further work to develop the CCMM should consider future developments in item content and scope on the extent of item overlap. Overlapping items (known as factorially complex) can be reworded to determine whether this reduces overlap. This should be considered, though the expected overlap between items that assess negative meaning and search for meaning needs to be borne in mind.

7.2.4 Component Structure

There is a need to examine the component structure of the CCMM with other clinical populations. One of the first priorities though for further development of this measure will be to collect data that would allow for a

confirmatory analysis to be conducted. This is particularly important in terms of further examining the item loadings. Examining results of confirmatory analysis and collecting data from patients on their responses could also assist with need to examine dual loading items. It is only with access to these data that definitive statements can be made about the performance of this measure and the stability of the underlying constructs. Robust evidence on construct validity will come from an examination of the performance of the CCMM in a range of studies of related constructs.

There is also a need to examine the extent of factorial variance (sometimes known as the replicability of the component structure) across age groups and cultures, as there may be variation in dimensions and CCMM response profiles. Although, it is likely that the CCMM subscales are relevant to a group of people with cancer in the West of Scotland, the profile of people living within a different country (even within the UK) may be different. Although Folkman has proposed that meaning might constitute a coping response for some people, there is much that needs to be learned about the links between meaning and coping with cancer.

It could be argued that the factorial complexity that is evident within the principal component structure constitutes a significant limitation in considering this work to develop the CCMM. This would certainly be the case if the psychosocial oncology literature were clear about how meaning should be conceptualised and if there were no evidence of conceptual drift or semantic confusion. It is precisely as a result of the semantic confusion, as well as the acceptance that meaning will overlap with and is a part of coping and adjustment that this factorial complexity is not regarded as a severe

limitation at this stage in the evolution of the CCMM. The measure has been developed to minimise reference to or the application of coping strategies. There has also been a definitive attempt to ensure that situational meaning are covered in preference to global meaning. The measure captures the complexity of situational meaning in that it can be used within work which conceptualises situational meaning as a mediator, moderator or an outcome variable.

7.2.5 Developing Numerical Indices of Response Profiles

Further work needs to be undertaken to examine the way in which the subscales on this measure might be combined to produce an overall numerical index. This could be progressed by considering the merits of examining profiles of response (as mentioned at section 7.2.3). Current knowledge about situational meaning is not sufficiently well advanced to be able to suggest ways in which the scores on this measure could be combined numerically. Different methods of scoring and interpretation could be examined within the wider context of exploring the relationships of the CCMM to established measures. This approach would involve the testing of hypotheses where an overall index of situational meaning could be produced by combining subscales and examining their relationship to other factors.
Although one might intuitively expect that higher positive meaning would counterbalance the effects of higher negative meaning, the extent to which these data could be used to inform the scoring guidance for the CCMM would need to be specifically evaluated.

Moss (1992) has argued that there is a danger of "technologisation of the human spirit". The need for further work on understanding how to quantify

and interpret components of the CCMM does need to be conducted with this warning firmly in mind. Until further data are produced to provide guidance how the proposed components of situational meaning might be combined, the CCMM subscale scores should not be combined to form a total score. Individual subscale scores should be reported instead. This scoring method is also used for the Illness Cognitions Questionnaire (Evers *et al.* 2001).

The wording of the items has been arranged so that the words "because of cancer" and "Cancer has made me ...." appear within items in a bid to ensure that respondents are considering the content of each item with specific reference to cancer. Although such attention to detail has been a feature of these initial stages of the development of this measure, there will be an ongoing need to begin to ensure that future research on the CCMM considers whether patient responses are being made on the basis of personally considered cancer specific factors. This can be a problem that is associated with self-report measures. Responses could be complemented by idiographic elements of assessment such as sentence completion. It is possible that the inclusion of a qualitative component to the CCMM could be of use in the interpretation of response profiles (in the same way that when asked to elaborate verbally on responses within the field testing phase of this research, the responses assisted with the interpretation of response patterns).

Emotions result from the ascription of meaning to events (Roseman & Evdokas, 2004). Links between response profiles and affective dimensions of experience need to be examined both from the perspective of validation but also to assist with the development and refinement of the ways in which clinicians might plan emotional and psychological care targeted at meaning

(see Foster & McLellan, 2000). Validation of a new measure can only be accomplished by examining data from a range of studies that use the CCMM. These data can then considered with regard to development of theory and relationships to other measures of meaning. Analyses of the patterns of performance across a range of studies will also allow for the development of a knowledge base on the psychometric status of the measure.

7.3 Conclusions

In addition to work that could be undertaken to develop a better understanding of the psychometric properties of the CCMM, there is a need to refine theories and examine the content and boundaries of the constructs that have been proposed to account for the patterns of response that have been observed within the three components of the measure. In addition to this, the overlaps between meaning, coping and adjustment and the confusion that sometimes exists in how these concepts are defined would suggest that examination of construct boundaries between these overarching constructs might be useful. The constructs that have been proposed within the CCMM also need to be examined with regard to current theories and models relating to meaning in psychosocial oncology. Recent interest in meaning based research will provide further opportunities for validation of the CCMM. This could also simultaneously contribute to the examination of links between global and situational meaning and also lead to refinements in understanding of how components of situational meaning relate to illness representations, coping and adjustment. These latter issues are also important clinically and the focus of the final Chapter will be on the utility and application of the CCMM for clinical psychology practice.

Chapter 8 Future Applications of the Core Cancer Meanings Measure and Its Conceptual Basis

8.1 The Clinical Utility of the Core Cancer Meanings Measure

8.1.1 Comparison Regarding Clinical Utility of Other Meaning Measures

8.1.2 Using the Core Cancer Meanings Measure in the Provision of Psychological Care

8.2 Potential Utility of Subscales and Item Content in Psychosocial and Specialist Psychosocial Care in Oncology

8.2.1 Negative Meaning Subscale

8.2.2 Search for Meaning Subscale

8.2.3 Positive Meaning Subscale

8.2.4 Profiles on the Core Cancer Meanings Measure

8.3 Contribution to Research on Core Meaning Themes and Physical Illness

8.4 Conclusions

This Chapter will consider the possible applications of the CCMM in clinical settings, considering the similarities, differences, strengths and weaknesses of the CCMM in relation to existing measures of global and situational meaning. This will be viewed from the perspective of clinical settings in general and then considering specialist psychological care services in cancer. The remainder of the Chapter will consider the content of the subscales that have been identified within the components, examining the possible relevance of content to the assessment, formulation and intervention phases in psychological therapy. There will be particular emphasis on cognitive behavioural interventions (reflecting the cognitive content of the scale) and reference to other psychotherapeutic modalities when relevant. Suggestions for 'single n' paradigms to further progress understanding of the process dimensions for this measure will also be outlined.

8.1 The Clinical Utility of the Core Cancer Meanings Measure

8.1.1 Comparison Regarding Clinical Utility of Other Meaning Measures

There is a diverse range of cognitive outcomes that might follow personally traumatic experiences (Bower *et al.* 1998). The application of the CCMM provides a fast and reliable way of gathering information on some of the common themes known to influence psychosocial adjustment to cancer. The brevity of this measure is one of its strengths and something that it has in common with other measures of illness related situational meaning such as the Illness Cognitions Questionnaire (Evers *et al.* 2001) and the Constructed Meaning Scale (Fife, 1995). Respondents are asked to indicate their responses for each item in accordance with the same choices, unlike the Sense of Coherence Scale (Antonovsky, 1993) or the Purpose in Life Test (Crumbaugh

and Maholik, 1964). This is likely to be important when the scale is being administered to patients with problems relating to fatigue or with limited concentration. The inclusion of an even number of response options will reduce the likelihood of having neutral responses, though it could be argued that this is also a weakness in clinical settings where uncertainty and indecision about cancer related meanings might be useful to know about. Although the content of the items on the CCMM addresses key dimensions of situational meaning, there is clearly a bias toward more negatively valenced content. Unlike the Constructed Meaning Scale (CMS) there are no gradations within responses to indicate level of disagreement. The CMS includes 'Disagree' and 'Strongly Disagree'. This could be an important distinction clinically when it is necessary to understand the degree of belief conviction relating to all responses and not solely those given an 'Agree' response. Unlike all of the other measures that were considered in Chapter 3, the CCMM is very specific in mentioning cancer in relation to each item. Respondents are more likely to provide responses that accurately reflect their thoughts in relation to cancer as a result (and not with regard to other elements of their experience that might be influencing their experience of similar cognitive themes). Items have been worded so that they can easily be incorporated within conceptual frameworks in cognitive therapy. Their responses on the measure will also facilitate inclusion in cognitive case conceptualizations and be open to direct evidence testing and intervention strategies applied with negative automatic thoughts (White, 2001). The fact that the CCMM was developed solely with people who have cancer, unlike the CMS or the ICQ, is a key strength and advantage for the future use and application of the CCMM in cancer care settings.

Application of this measure will enable profiles to be outlined and clinicians can identify areas for further assessment and/or prioritise therapy goals. Responses on the measure could be interpreted alongside other clinical information and this could inform case formulation efforts. Cates (1999) has suggested that although standards of reliability and validity consider individual assessment measures, they do not take account of the wider context and the need to integrate data from other sources within a comprehensive assessment. Clinical applications of the CCMM might provide data on the ways in which other assessments can complement the CCMM for planning a response to an identified psychological need. An example of this might be the endorsement of 'Cancer is a death sentence' by a patient who had localised disease and a good prognosis. This could lead to the hypothesis that their depressed mood was being mediated by negative predictions about disease course, based on memories of cancer and illness experiences earlier in their life. (Brewin *et al.* 1998). Responses on repeat administration of the measure could be used to consider changes following psychological therapy, an important use in view of current emphasis on evidence based practice. It is likely that psychological therapists could benefit from the information that the CCMM would provide. Examination of profiles of response on each of the subscales could lead to a number of possible actions with regard to assessing, understanding and intervening with psychological problems relating to cancer. Clinicians would also benefit from guidance on the circumstances in which the application of the CCMM might complement data obtained from other clinical psychological assessment measures such as the MAC.

8.1.2 Using the Core Cancer Meanings Measure in the Provision of Psychological Care

There are a number of ways in which this measure might be applied to the general clinical care of people who have cancer. This is best conceptualised in terms of understanding generic and specialist psychological care. Generic psychological care relates to the care provided by all health professionals whereas specialist psychological care relates to more comprehensive assessment and therapy provided by those with post qualification training in therapeutic counselling or clinical psychology. The CCMM has the potential to be usefully applied by those involved in generic psychological care and also with more specialist work.

Measures that are developed in research settings are not always easily used within clinical settings (Higginson & Carr, 2001). In the United Kingdom the average duration of an oncology out patient consultation is between 10 and 15 minutes (Jones, 2001). Although the routine application of the CCMM is more likely to be of use to mental health professionals working in oncology than it would be to medical and nursing staff, medical and nursing practitioners who have undertaken further training in psychological care might choose to use the CCMM when they wished to explore meanings in greater detail and/or identify issues that they would then be able to assess using questioning. Taylor (1993) has suggested that "oncology nurses must understand how to care for those who search for meaning". Nurses who use this measure to structure their interactions with patients might find that it enabled them to focus on sensitive issues and tailor their discussions to patient dimensions of meaning. Stark and House (2000) have suggested that "it is helpful to explore the meaning patients attach to events" (p1266). O'Connor and Wicker (1995)

have even suggested that this should be a core objective in training and developing nurses to deliver psychological care.

It is well recognized that there are problems relating to the abilities of cancer clinicians to recognize and respond appropriately to psychological concerns that are experienced by people who have cancer. Much has been written about training cancer clinicians in developing communication skills and in work to improve the management of clinical scenarios such as those relating to breaking bad news (Fallowfield *et al.* 2002). Although these often focus upon enabling clinicians to enhance assessment and communication skills that involve the style and content of their utterances within consultations, it would also be possible to enable them to become confident at integrating self report measures as an adjunct to the work that they may be undertaking to reduce behaviours that inhibit disclosure.

There has also been some work that has started to look at prompt sheets for people with cancer. These have been shown to enhance satisfaction with consultations in the short term (Bruera *et al.* 2003) and also with regard to addressing anxiety and quality of life among people with incurable cancer (Clayton *et al.* 2003). Completion of the CCMM might act as a prompt for patients to disclose psychosocial concerns related to the themes within it. This could be examined with further research. The application of the measure before a consultation might help clinicians to conduct consultations that are more sensitive to psychosocial dimension, thus addressing some of the issues raised by Ford *et al.* (1994).

In recent years there has been an increasing emphasis on the need to evaluate the outcome of clinical interventions within clinical psychology and psychotherapy (Barkham & Mellor-Clark, 2003). Within clinical psychology there is a long established history of developing self-report assessment measures that are used for the evaluation of outcomes. Collections of commonly used self-report assessment measures have been published in volumes such as the 'Practitioners Guide to Empirically Based Measures of Anxiety' (Antony *et al.* 2001) and the Measures in Health Psychology Portfolio (Weinman *et al.* 1995).

Within cognitive psychotherapy it has been suggested that there is a need to utilise self report measures of cognitive content and not solely symptom based measures that provide detail on the presence or severity of symptoms. The importance of data from self-report measures of cognition has been highlighted with regard to the importance of conceptualizing the mediators and moderators of psychological problems (Dozois *et al.* 2003). The CCMM is particularly relevant in considering the outcome of psychotherapies that specifically target meaning, though could potentially be applied to all psychotherapies in view of Brewin and Power's (1999) suggestion that changed meaning occurs with a range of therapy modalities.

A range of eclectic approaches to psychological therapies in cancer has been shown to result in positive psychosocial benefits (Meyer & Mark, 1995). There is a need to begin to deconstruct components of psychological interventions and better understand the factors that contribute to positive outcomes. The CCMM could be used as an outcome measure for this purpose in clinical effectiveness based trials and to evaluate meaning based group therapies such

as those being developed by Breibart and colleagues (Greenstein & Breitbart, 2000). Work with this focus would provide an ideal vehicle to explore whether the CCMM has clinical utility as a psychotherapy outcome measure. Hayes *et al.* (1987) have suggested that assessments can have an impact on eventual treatment outcome (referred to as 'treatment utility') and that this too should be part of the initial validation of a new measure. The utility of responses on the CCMM could be evaluated with regard to decisions within therapy.

It is also possible that responses on this measure might assist clinical psychologists (and other psychological therapists working within cancer settings) to consider the way in which patient profiles on the measure might inform subsequent components of their case management. However, this measure (and any self report measure that is based on the endorsement of predefined items) can provide only a general indication to the thoughts experienced by patients. Responses need to be considered further as part of a process of understanding idiosyncratic aspects of a patient's cancer experiences.

The next section will consider each of the subscales within the CCMM, focusing specifically on the content of items and the way in which this might be linked with clinical assessment, formulation and intervention. Clinical psychologists (and particularly those practicing within the cognitive behavioural model) act as scientist practitioners. Examples of the ways in which single case methodologies might inform clinical psychological care will be outlined when relevant.

8.2 Potential Utility of Subscales and Item Content in Psychosocial and Specialist Psychosocial Care in Oncology

8.2.1 Negative Meaning Subscale

Patients who endorse any of the 'Agree' items on this subscale are likely to be experiencing problems with illness intrusiveness (e.g. 'Cancer rules my life'; 'Cancer interferes with living my life'), helplessness and loss of control (e.g. 'I have lost control of my life because of cancer')All of the items suggest a number of specific clarifying questions that could be asked in order to appreciate the precise emotional and behavioural manifestations of the thoughts that have been endorsed. Respondents could be encouraged to outline examples that illustrate the experiences that have contributed to their responses. In some instances it will be possible to highlight biases within information processing and in so doing engage patients with a cognitive model to understand their experiences. Assessment content could focus upon the ways in which daily functioning is negatively influenced by cancer. It is possible that patients expressing agreement with the thoughts on this subscale would notice that cognitive therapy targeted at one or two aspects of negative meaning would result in simultaneous changes in other cognitions (something that could be evaluated using a multiple baseline design). An example of this might be working with a patient to address their perception that cancer rules their life and simultaneously monitoring conviction with the other items (e.g., 'I have lost control of my life because of cancer').

In view of the importance of facilitating emotional expression as an element of cognitive psychotherapy for cancer (Moorey & Greer, 2002) and in detoxifying death as an element of supportive expressive psychotherapy (Speigel & Classen, 2000), respondents endorsing agreement with 'Cancer is a

death sentence' could be provided with the chance to express their feelings in relation to this and its personal significance. The interaction between cancer, psychosocial status and social support or relationship quality is of course well recognized and it may be the case that patients who endorse the subscale items about other people's views ('Other people pity me because I have cancer') are doing so with specific reference to this (Trunzo & Pinto, 2003). Cognitive therapeutic work might therefore need to address self and other schemata that contribute to symptoms. Sessions with family members could also be integrated in such cases, particularly where patients name specific others that they had in mind when they responded to these items.

8.2.2 Search for Meaning Subscale

The content of the items that are components of the 'Search for Meaning' subscale are related to much of the work that has been undertaken in understanding psychological adjustment to trauma. Here the emphasis is on understanding the way in which an event has been assimilated within existing beliefs. For some patients this will relate to an inability to assimilate their cancer experience with a prior world view ('My world has fallen apart because of cancer'), manifest by statements that reflect the view that the distribution and incidence of cancer should conform to rules or principles of a 'just world' ('It is not fair that I developed cancer'). When this does not happen patients may find that they become preoccupied about their cancer and its effect on their lives. This may include thinking about whether their cancer has spread. Endorsement of items that imply preoccupation or rumination may lead to the assessment and formulation of metacognitive aspects of information processing and consideration of the possible benefits of mindfulness based interventions (Ma &Teasdale, 2004). Endorsement of items that suggest this

may be a relevant issue in understanding adjustment could lead to monitoring of the amount of time spent thinking about cancer and the possibility of arranging ABA single case designs that enable patients to appreciate the influence of thought control strategies on their awareness of cancer related thoughts. Blampied (1999) has outlined the case for using single case methodologies within cognitive psychotherapy. Responses on the CCMM are also likely to lead to the need to consider links with global meaning and it is in such circumstances that the application of the Life Attitude Profile-Revised might be most productive. Many authors have outlined suggestions to deal with uncertainty associated with cancer progression and recurrence (Faulkener & Maguire, 1994; Moorey & Greer, 2002) and it is these that could be used to plan care elements of patients whose endorsement of 'I wonder if my cancer has spread' suggests problems with this element for situational meaning.

8.2.3 Positive Meaning Subscale

Clinicians might wish to have patients elaborate on 'My cancer philosophy is live for today' for the purpose of understanding the extent to which this way of thinking is reflective of a longstanding belief or whether cancer experiences have in any way contributed to a change in life philosophy. Here the potential to examine the range of possible responses is highlighted. If a patient does not agree with this item then it may reflect a degree of reactance to what they have been told about their prognosis. Here too there is a need to allow patients to elaborate on their responses for the purpose of understanding emotional dimensions of situational meaning. Responses to this subscale would allow for the disclosure of information on specific manifestations of items such as 'My life has more meaning because of cancer'.

Although the literature on benefit finding and post traumatic growth is equivocal as to whether it is advisable for clinicians to foster this way of thinking within patients, it is possible that some patients may express views reflecting their need to change from having no positive meaning elements to being able to identify with and experience some of the thoughts that are associated with changes in life philosophy, attentional focus and a more positive outcome. Patients could be helped to evaluate the impact on mood and other thoughts by engaging in some experiments that test the impact of manipulating thought content.

8.2.4 Profiles on the Core Cancer Meanings Measure

Although it is possible to begin to make some links and suggestions about the psychological care that might be provided according to response profile on this measure, there is also a need to more formally examine the way in which the overall profile of responses on this measure changes in accordance with participation in the common forms of psychological therapy that are applied within cancer settings. From a clinical perspective there is the need to develop guidance for clinicians on how to interpret profiles of scores on this measure and the way in which clinical interventions might be tailored to patients in accordance with the profile of responses that are evident on the CCMM. The application of a self- report measure to this clinical activity can be seen in the approach that has been taken in the writing of self-help materials for patients that have experienced surgery resulting in the formation of a stoma (White, 1997; 2002). This work was based on research that developed a measure of stoma related thoughts and specifically those that were most related to distress (White & Unwin, 1998). It is possible that

the thought content within the CCMM could be used to structure similar self management advice.

8.3 Contribution to Research on Core Meaning Themes and Physical Illness

Two of the main theories regarding the role of situationally linked thoughts and adjustment to cancer are the social cognitive model of adjustment to cancer (Brennan, 2001) and the meaning based model of coping outlined by Park and Folkman (1997). Brennan (2001) specifically outlines the issues as they relate to cancer. Park and Folkman's model is not cancer specific. It appears that the CCMM provides useful data to assist with the further refinement of these models and their application within cognitive therapy and psychosocial oncology.

Brennan (2001) has suggested that it is important to develop an understanding of the cognitive processes that relate to the process of adjustment to cancer. He has emphasized the importance of examining individual processes of change with each person affected by cancer. The components of the constructs assessed by the CCMM are highly relevant to this process of understanding adjustment. Information on meaning might be helpful in resolving some of the issues that Brennan refers to as "the paradox of apparently divergent outcomes" (p.3). The content of CCMM subscales are consistent with the work of Collins *et al.* (1990); Janoff-Bulman (1989) and Taylor (1993). They have all reported that people with cancer reported both positive and negative changes following cancer.

Brennan (2001) talks of the fracture of core assumptions that can occur following diagnosis and the various ways in which this might be resolved in a positive or negative manner. The core assumptions that he describes are life trajectory, self control/worth, the nature of attachments and spiritual or existential issues. The social cognitive model outlines how some people experience negative psychological adjustment in response to the dissonance that is created when their assumptions are challenged and contrasts this with the positive emphasis that can be seen within the adjustment patterns of other patients who experienced similar challenges to their assumptions.

All of these assumptions can be appreciated within the content of the CCMM items. Cancer tends to challenge assumptions about anticipated life trajectory. For some, this leads to a revision of priorities in life and new motivational structures ('My cancer philosophy is live for today'), though for others this can become a factor that dominates their day to day thoughts and causes hopelessness ('Cancer rules my life'). While there are some patients who are able to retain feelings of self-control and worth for most of their cancer experiences ('Cancer has made me really focus on what matters in life'), there are a substantial minority of others where loss of control becomes a significant influencing factor ('I have lost control of my life because of cancer'). Cancer (like many other physical illnesses) has an impact on the nature of the significant emotional attachments that the person with cancer has with others in their lives. The social and family support that is experienced by some patients can act as a significant personal resource and for others the lack of such support leads of feelings of isolation and loneliness ('Other people pity me because I have cancer'). Data from patient responses on the CCMM could be related to the social cognitive model. The measure

could also provide a useful way of gathering further empirical evidence to validate applications of the model as outlined by Brennan (2001).

The heuristic model proposed by Park and Folkman (1997) to account for the potential interactions between global and situational meaning has already been outlined. Although their model emphasises 'meaning-making coping' there are some parallels with the proposed component structure of the CCMM and the content of the model. The relationship of the CCMM item content, loading on components and Park and Folkman (1997) was addressed in Chapter 6. If a method of assessing whether situational meaning was congruent with global meaning could be developed (a key element of the Park and Folkman (1997) model), it is likely that the SFM component of the CCMM would provide data to refine and develop the model in more detail. The challenge in examining the utility of Park and Folkman's (1997) model and developing it further relates in part to the dynamic processes that are outlined within it. Further work is also needed to examine how the model might be applied to different illnesses.

The fact that the CCMM includes items that reflect a positive dimension is consistent with the growing literature on the positive 'benefits' that can be associated with cancer experiences (Thornton, 2002). Affleck and Tennen (1996) have distinguished benefit finding from benefit reminding. The positive meaning element of the CCMM (and the other subscales for that matter) does not distinguish between benefit finding or reminding. Further development of the CCMM is likely to be informed by the increasing number of studies that are examining positive meaning components such as benefit finding, benefit reminding, post traumatic growth and positive reappraisal coping. It has

been suggested that some patients use benefit finding as a coping strategy. It cannot be assumed though that patients who endorse CCMM items relating to benefit finding (or any other positive meaning item) use this as a coping strategy (Sears *et al.* 2093). Endorsement of these items on a questionnaire could be linked with the use of an element of cancer related meaning as a way of coping. On the other hand and in the present absence of any data on the relationship between responses on the CCMM and coping, such endorsement only indicates that when confronted by pre-defined options on a forced choice questionnaire that these items were endorsed. This illustrates the need to have more data on the relationship of performance on the CCMM with elements of positive meaning, particularly those that assess positive reappraisal coping and posttraumatic growth.

The importance of 'downward temporal comparison' also needs to be considered in future work on benefit finding. It has been suggested that data on benefit finding may be the result of someone downgrading their former self (Davis & McKearney, 2003) as opposed to the experience of perceiving benefits but in the absence of changes in other beliefs. Although there is the appearance of benefit finding, this could be the result of a process whereby elements of belief systems are re-organised and ranked in a different manner (as opposed to the discovery of benefit that is immediately afforded greater status than pre-event belief themes). It is only with longitudinal studies that these processes could be examined. Here one would expect that, if Davis and McKearney's observations are correct, measurements suggesting post traumatic growth (whether in the form of benefit finding or not) would be accompanied by evidence of their being simultaneous negative changes on measures of other global belief systems. The CCMM would provide a useful

way of examining changes and testing specific predictions about changes in meaning 'profiles' immediately following a cancer diagnosis. Other predictions relating to this are that those with greatest change in premorbid self related factors (more downgrading of premorbid beliefs) would experience benefit finding of a greater magnitude. It is also possible that knowing a greater amount of information about pre-trauma beliefs and assumptions at a global level would be of interest in understanding subsequent adjustment to disease. Unfortunately there are few normative data to guide such research on the belief structures of those outside of clinical settings. There are no normative data on non traumatised populations for the World Assumptions Scale (Carboon, personal communication).

The processes that are associated with the search for, construction of and derivation of meanings are likely to be similar across different illnesses (and other life experiences). The content and the balance of content (i.e., positive or negative) are likely to differ in accordance with the individual, illness or event that has been experienced. There are also some interesting questions that arise in terms of whether someone with cancer would have the same meaning response pattern if they had experienced another illness. Here, the links with cancer specific meaning and cancer illness representations are pertinent and ripe for exploration. Developments in the theoretical understanding of this work will also need to address how generic elements of illness related situational meaning are generated (i.e., how much is determined by dispositional traits and how much by contextual interactions) and account for any illness specific variations in content. It is possible that core cancer related meaning is generated in part by general global meaning

structures and that specific appraisals or interpretations are the result of site specific beliefs and experiences.

Further refinement and development of the CCMM should be undertaken alongside work that develops and integrates new and expanded theoretical perspectives on meaning. The themes that are apparent within the subscales of the CCMM are being recognized as applicable to the psychological experiences of people with other physical illnesses. These constructs identified here are likely to be applicable across a range of physical illnesses other than cancer, particularly in view of the suggestions that there may be a generic meaning structure within the cognitive experiences of those with physical illness (Evers *et al.* 2001). The approach adopted by the EORTC in their work on assessment of quality of life (where there are core and cancer site specific versions of a quality of life questionnaire) could be considered as a way of approaching this issue. Here the guiding principle would be that there was a core cognitive dimension that related to adjustment to illness and that this was different according to the illness being examined. This way one would have a core illness cognition profile (broadly similar across illnesses but with specific subtle variations according to illness type) and specific cognitive dimensions that were unique to that illness. For cancer it is likely that these would be related to disease specific issues such as fear of recurrence. This would be different for other diseases; for example, with multiple sclerosis this might be paralleled by other fears, e.g., fear of incontinence.

Meaning has also been examined with regard to psychological response to physical symptoms. Chen (2003) reported that meaning ascribed to cancer related pain was a key determinant of level of hope. It is possible that

patients with a range of physical symptoms might have a different secondary psychological response on the basis of the meaning that they experience in relation to their cancer. The content of the CCMM might provide a useful framework within which to explore meaning specifically in relation to cancer symptoms. There is work that has been undertaken on the precise meaning elements for cancer pain that might be useful in developing specific classifications for pain related meanings - e.g., pain as predetermined fate, as a random occurrence or as the result of God's will (Ferrell *et al.* 1993). Here there is potential for a complex interaction of beliefs as one begins to consider meaning in relation to cancer and to the other common physical symptoms seen in cancer, e.g., fatigue.

8.5 Conclusions

The CCMM has potential applications within cancer care settings as a tool to help staff understand a patient's psychological experiences and to increase the chance of them being able to tailor care in a way that takes account of the meanings that they have experienced in relation to cancer. It could also be used within specialist psychological care settings to assist with case conceptualisation and assessing the therapy process. The conceptual basis of the CCMM is supported by some of the current models of cognition and meaning that have been applied to psychosocial adjustment among people with cancer. The identification of components relating to negative meaning, search for meaning, the links between these components and a further component relating to positive meanings, provides support for the need to examine and refine conceptual models of situational meaning and further develop the CCMM as a reliable, valid and relevant assessment measure.

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Appendices

1. Sample Declaration of Agreement from Consultants in Clinical or Medical Oncology
2. Approval from West Ethics Committee of West Glasgow Hospitals University NHS Trust
3. Information Sheet for Patients who Expressed an Interest in the Research
4. Sample Consent Form for Participation
5. Sample Consent Form for Audio taping of Interview
6. Agreement with Independent Transcription Company
7. Protocol for Conducting Interviews to Elicit Information for a Pool of Items
8. Sample of Full Transcript from Interviews Conducted to Generate Pool of Items
9. Sample of Node and all Patient Utterances that are Collected within NUD*IST Software at that Node
10. Letter Sent to Clinicians in Peer Review Group, with Initial Version of Core Cancer Meanings Measure
11. Protocol for Field Testing Phase
12. Core Cancer Meanings Measure for Field Testing (55 item version)
13. Full Results of Information Obtained During Field Testing
14. Core Cancer Meanings Measure for Main Validation Phase (40 items)
15. Percentage of Responses Endorsed for Each CCMM Item
16. Percentage of Responses Endorsed by Tumour Site and Disease Status for Each CCMM Item
17. Ethical Approval from Ayrshire & Arran Research Ethics Committee
18. Information Sheet for Main Validation Phase
19. Consent Form for Main Validation Phase

Appendix 1.2

Content of Declaration of Agreement Signed By Consultants listed in Appendix 1.1

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cancer
research
campaign

DEVELOPING A COGNITIVE MODEL OF PSYCHOSOCIAL ADJUSTMENT TO CANCER

Dr. Craig A. White, CRC Fellow in Psychosocial Oncology
Prof. Colin A. Espie. Professor of Clinical Psychology
Prof. Stanley B. Kaye, Professor of Medical Oncology

DECLARATION OF AGREEMENT

I have read the protocol outlined in the submission 'Developing a Cognitive Model of Psychosocial Adjustment to Cancer' which is being submitted Dr. White, Prof. Espie and Prof. Kaye to the West Ethics Committee for approval. I am happy for any patient under my care who meets the inclusion criteria and who gives their written consent, to take part in this research.

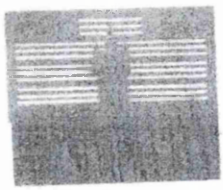
Signed: _____

«Title». «FirstName» «LastName», «JobTitle».

Date: _____

Please return this to Dr. Craig White at the address printed below.

DEPARTMENT OF PSYCHOLOGICAL MEDICINE
Academic Centre, Gartnavel Royal Hospital. 1055 Great Western Road, Glasgow, G12 0XH



West Glasgow Hospitals University NHS Trust

WEST ETHICS COMMITTEE
Western Infirmary
Dumbarton Road

Glasgow G11 ANT

Direct Line: 211 6238
Fax: 211 1920

Our Ref: AHT/JR

Your Ref:

Please reply to: Mrs A H Torrie
SECRETARY - WEST ETHICS COMMITTEE

20th January 1999

Dr Craig A White
Department of Psychological Medicine
University of Glasgow
Glasgow

Dear Dr White,

Protocol No.98/222(2) - Development of a cognitive model of psychosocial adjustment to cancer.

The Committee at its meeting held on 19th January, 1999 discussed and approved the Amended Patient Information Sheet for the above study enclosed in your letter dated 13th January, 1999. This study now has full Ethics Committee approval.

With kind regards.

Yours sincerely,

Andrea H Torrie

Andrea H Torrie

SECRETARY WEST ETHICS COMMITTEE (2)

Appendix 3
Information Sheet for Patients who Expressed an Interest in the Research

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THIS SHEET HAS BEEN APPROVED BY THE WEST ETHICS COMMITTEE INFORMATION SHEET FOR PATIENTS/VOLUNTEERS IN CLINICAL RESEARCH PROJECT

Brief Title of Project

DEVELOPMENT OF A COGNITIVE MODEL OF PSYCHOSOCIAL ADJUSTMENT TO CANCER

You are being invited to participate in a study which we are carrying out on behalf of the Cancer Research Campaign and the Department of Psychological Medicine at the University of Glasgow. The aim of the study is to understand more about the way cancer and cancer treatments affect the way people think. Previous research has shown that having cancer can lead to problems such as anxiety and depression and that these problems are often associated with particular thinking patterns. This research aims to improve our ways of assessing the way people think about cancer, so that psychological treatments can be improved. If you decide that you want to participate in this study then you will be asked to sign a consent form indicating that you agree to take part. The next step will either involve meeting with Dr. Craig White, a Cancer Research Campaign Fellow from the University Department of Psychological Medicine or completing some questionnaires and returning these (you will be told which of these arrangements applies to you). If you meet with Dr. White you may be asked for your permission for the interview to be recorded on an audio tape. The content of this tape will be converted later to a written account of the interview. Your name will not be attached to the tape and it will be stored securely under lock and key. Involvement in this study will take up approximately one hour of your time. The focus of the research will be on your thoughts, feelings and behaviour with regard to your experiences of having cancer. If the research identifies any problems with how you are feeling, thinking or coping with cancer then Dr. White will discuss how you may be able to get some help with this if you want to.

The interview and questionnaires focus on your feelings, personal opinions and thoughts about cancer. Taking part in this study may not be of direct benefit to you, but could help in the development of psychological assessment and treatment methods for future patients. All information you give as part of this research will be treated as confidential and your name will not be attached to this. If you do not wish to participate in this study, or wish to withdraw at any time after becoming involved, your care will in no way be affected. If you wish to take part in this study then your Consultant Oncologist and GP will be informed of this. If you want to discuss this research further or you have any questions which you would like answered then please contact: Dr. Craig A. White, Department of Psychological Medicine, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12
0XH or call him on 0141 211 0694.

Appendix 4
Sample Consent Form for Participation

CONSENT FORM

DEVELOPMENT OF A COGNITIVE MODEL OF PSYCHOSOCIAL ADJUSTMENT TO CANCER

By signing this form you give consent to your participation in the project whose title is at the top of this page. You should have been given a complete explanation of the project to your satisfaction and have been given the opportunity to ask questions. You should have been given a copy of the patient information sheet approved by the West Ethics Committee to read and to keep. Even though you have agreed to take part in the research procedures you may withdraw this consent at any time without the need to explain why and without any prejudice to your care.

Consent:

I,.....(PRINT)

of.....

give my consent to the research procedures above, the nature, purpose and possible consequences
of which have been described to me

by.....

Patient's signature.....Date.....

Doctor's signature.....

UNIVERSITY
of
GLASGOW

cancer research campaign

Development of a Cognitive Model of Psychosocial Adjustment to Cancer
Protocol No 98/222 (2)

CONSENT TO AUDIO TAPE AN INTERVIEW

I, _____ (Name)

of _____ (Address)

_____

consent to an audio tape being made of my interview with Dr. Craig A. White, CRC Fellow in Psychosocial Oncology on _____ (insert date).

I understand that this tape recording will be used for research and/or professional education and training (delete as applicable) and that the tape will be stored securely within the University Department of Psychological Medicine. I also understand that I can request that this recording be destroyed at any time.

Signed _____

Date _____

Signed _____
Dr. Craig A. White, CRC Fellow in Psychosocial Oncology

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GLASGOW

cancer
research
campaign

Development of a Cognitive Model of Psychosocial Adjustment to Cancer
Protocol 98/222(2)

COLLECTION AND DELIVERY OF AUDIOTAPES

Tape Serial Numbers:

Letter Sent:

Date of Collection:

Signed: _____

Print Name: _____

on behalf of University of Glasgow

Signed: _____

Print Name: _____

on behalf of Nine to Five Secretarial Services

Date of Return:

Signed: _____

Print Name: _____

on behalf of University of Glasgow

Signed: _____

Print Name: _____

on behalf of Nine to Five Secretarial Services

Appendix 7
Protocol for Conducting Interviews to Elicit Information for a Pool of Items

Patients were initially invited to provide detail on the chronological sequence of events leading to their contact with the cancer unit in which the research was being undertaken. The main reason for this was first, to provide the researcher with background information on important patient information regarding diagnosis and management and second, to provide a chronological structure which could be used to structure further elements of the interview. Beginning the interview in this manner also provided the opportunity to evaluate the personally salient events recalled by patients when asked to summarise significant events regarding their experiences of cancer.

In keeping with the researchers aim to adhere to core components of cognitive therapy process, this initial information provided by patients was then summarised to check accuracy and establish a collaborative therapeutic alliance upon which further detailed questioning could be undertaken throughout the research interview.

When details on patients experiences had been elicited (and any researcher uncertainties clarified) the interview proceeded to examine the impact of living with cancer. Patients were asked to report any day to day problems that they had experienced following their diagnosis of cancer.

What were the main sorts of day to day problems that the cancer and the treatment caused ?
What would you say has been the day to day impact of the cancer and its treatment on your life ?

Patient problems were explored by the researcher, with particular emphasis on determining the emotional, cognitive and behavioural elements of their experiences.

And how do you feel about that, him taking over in that way ?
And how has that made you feel emotionally, the fact that you are very limited ?
And how did that make you feel having to depend on others and not being able to do what you used to do?
Would you be able to tell me what a couple of those negative thoughts are in that 'downward spiral' ?
What do you think to yourself ?
What sorts of things do you think in terms of 'if only' ?
What sorts of things are going through your mind as you're lying in your bed ?

In addition to eliciting the main cognitive behavioural features of an individuals experience, the interview sought to elicit information on past cancer history, family history of cancer, living situation and information to facilitate sociodemographic classification (primarily level of education and occupation). This information was elicited either when this had been mentioned or alluded to by patients (e.g asking about prior employment arrangements when a patients discloses concerns about not being at work) or explicitly asked about when these themes had not yet appeared in the interview.

And what were you employed as ?
Has anyone else in the family ever had cancer ?
And prior to this had you ever had cancer before in your life ?

When it seems to the researcher that no further useful information was being elicited with regard to cognitive, behavioural or emotional aspects of their experience patients were provided with an explanation of the sentence completion element of this interview.

What I've got now is a list of sentences about cancer and cancer treatment. So what I'd like you to do is just complete them in your own words, just saying whatever comes to mind. .....

What I'd like you to do now ... I've got a list of sentences which aren't complete. What I'd like you to do is complete them with whatever comes into your mind, there's no right or wrong answer, I'm just interested in what you think.

This component of the interview was also designed to assess cognitive components of patient experience, but instead of using patient responses to interviewers questions, patients were invited to respond to sentence stems. The sentence stems which were used appear in the table below.

Sentence Stems
Having cancer means that .....
When you get cancer, you ....
Cancer is caused by .....
Cancer is ....
When I think of cancer, I think of .....
People who get cancer .....
Before I developed cancer I thought ....
My cancer was caused by .....
Cancer treatments are .....
The main effect of cancer on my life is .....
As a person, I am .....
When I think about how I feel about myself, I would say I feel ....
When I think of other people in relation to my cancer, I think .....

The researcher made notes of patient responses to sentence stems that required further exploration. This was done by summarising the way in which a particular sentence stem had been completed and inviting patients to elaborate on this.

You know you were saying that before this happened you thought that you were the luckiest lady in the world - what specific things in your life made you think that ?

You were saying that you sometimes think of younger people who have had cancer. What sorts of things do you find that you think about ?

You mentioned a couple of things - the process of taking stock. With your own experience, what sorts of things went through your mind as you take stock of things ?

In some cases this elaboration resulted in further information which could then be explored with regard to cognitive, behavioural or emotional components. If this was the case, then these components were explored by asking similar sorts of questions to those that were asked in response to personally salient events and/or cancer related problems.

When I said to you 'when I think of cancer', you said you think of other people and what types they might have, you don't automatically relate it to yourself. Can you tell me a bit more about that ?

(respondent answer, followed by ..)

And how did you feel about that, the fact that everyone else was telling you what to do ?

You also mentioned that when I said 'My cancer was caused by ....', you said 'the sun'. How do you feel about that ?

You mentioned that when you think of cancer you think of yourself and then others you know. Can you tell me a bit more about the other people you know and how that has an impact on you ?

For some patients, the research interview resulted in the disclosure of psychological signs and symptoms that required further screening assessment. In these cases, the researcher carried out further assessment in order to determine the most appropriate steps regarding further clinical management (e.g., liaison with the oncology team or referral to psychological/psychiatric services).

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(respondent answer, followed by ..)

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Appendix 8
Sample of Full Transcript from Interviews Conducted to Generate Pool of Items

T1508: 1023/1144231

Okay, well I should say that the only thing I know at the moment is your name and address and the fact that you were coming here today, I don't have any other information. So what would be helpful to start with is if you could tell me in your own words the events leading being in contact with the Beatson in terms of who you've seen, what for ...

Are you talking about operations? As far back as that?

Yes, because I don't know anything; the fact that you've had an operation is news to me.

Well, it would be about this time last year ... you were running back and forward to the toilet quite a lot, it was as if you were bursting for the toilet, but when you went you couldn't do anything. When you did do anything, it was very little. So I thought it was piles, a friend of mine had something similar and it was piles he had. And I went to my local GP, Dr XXXXXXX; he immediately wrote out a letter for the hospital. I went up there and had a barium enema, and what they call a secondary examination. And when that examination was finished the same day they told me I'd need to come in for an operation; there was something there, they thought it was a tumour. And this is what it was. So I went on the Monday, I had tests leading up to the Friday, and I had the operation on the Friday, which was July XXXXXXX I think. After the operation I'd to wait about a week for results from the lab, and Mr XXXXXXXXX the surgeon came in and said well, he was quite happy, everything was away as he thought, but he can't guarantee. So he advised me to get this treatment, the chemotherapy, which I had up at Monklands. I had three courses of that at the Monklands, you weren't kept in overnight, you were just in the afternoon, and then I had a gap, Dr XXXXX wanted me in here. I saw Dr XXXXX at first and then it was Dr XXXXX wanted me in here. Since then I've been coming in here on a fortnightly basis up until now. She had told me I'd get a scan after three sessions here, and another scan after six, so the first can was quite satisfactory and she was more than pleased with the second scan. But she said I'd rather you do the eight courses rather than the six, just as a precaution. So this is me back for the eighth and as far as I know, after I leave here on Wednesday ... the doctor I saw this morning said she'd make an arrangement to see Dr XXXXX at the Monklands as an outpatient, maybe in a month or six week's time. And I don't know whether she'll do another scan or what she'll do, but she seems quite happy, I'm

quite happy too. So that's about it.

And what sorts of day to day things have been affected by first of all the surgery and then the chemotherapy?

Coming out of the hospital after the operation, it took a wee while for your bowels to start moving again. You found that you were maybe at the toilet too often, but that's the way everything came about, but the chemotherapy ... I haven't really been affected by it, as some people have, such as loss of hair. You feel sick at times, in the early stages if somebody had cooked your favourite meal you couldn't stick the smell of the cooking, plus the fact you couldn't face the meal. Your appetite comes back not bad, but all through that time from the last August until now you've had a sort of tastelessness now and again. It's gradually wearing off, but it's a hard thing to explain, it's like diabetic chocolate, if you've ever tasted it, it's tasteless, and you sometimes feel this can put you off eating; sometimes you feel you can't be bothered eating this meal, this sort of thing. But going to the toilet, your bowels are more or less regular now, you do get the occasional touch of diarrhoea and it goes to constipation, and it balances itself out. But I don't know if that's the chemotherapy or whether that'll sort itself out once I come off it. But in general I've been feeling all right. I've never really looked upon this cancer as cancer.

How would you say you've looked at it?

A friend of mine who was in the XXXXXXXXXX, he had XXXXXXXXXXXXX, and he's dead now, he died. As he said 'you've got to be positive', which you try to do ... but the doctor had told him the trouble he had, he's either got a year or ten years out of it, which sounds a bit brutal, but at the same time you're betting being frank, you know? But unfortunately he died around November, but I've always thought you've got to be positive, because I think if you go into a room and just sit staring into space, it doesn't help you.

And what sort of things do you find helps you to remain positive?

I like working in the garden, although we've just come through the winter but coming into the gardening time again I'll probably be back out tidying up and things like that. It always takes your mind off it, and you do things at home too such as decorating - the only thing is that I did a bit of decorating before the end of the year, and you found that if you sat down for a wee rest you couldn't get up again, I find the tiredness hits you quite a bit. Not late at night, I find the tiredness can hit you at any time during the course of the day. You can sit down to watch the

midday news or whatever, and finish up waking up an hour later, this kind of thing. But I've always been active and I'm never a great one for watching television. There again maybe I've been fortunate, I dare say maybe if it was more serious, maybe you would just go into a depression or whatever you call it, but so far I've been all right that way, can't complain.

So the main impact really has been on things like tiredness and your appetite being affected, and this tastelessness....

Half the time now it's all right, but I find if you take things like a wee sherry, your taste will come back! I've found with chewing gum, if you take chewing gum it takes this flat taste away, makes you look forward to your meal when it comes along.

And any other ways in which your life has been affected or changed by this cancer?

Well, I've been lucky in as much as my wife has looked after me. I lost a bit of weight before I went in to the hospital, I lost about a stone, I was always around the XXXXXXX mark. I lost a stone, and I lost more stone when I was in there - I went down to XXXXXXXXX by the time I got out of hospital, and although you feel the better of the weight loss, you don't want to lose it that way. So of course she was obviously worried and a bit anxious, and she lost a bit of weight too, but my weight now is back up to XXXXXX stone. So since I came in here I've never really went down the way, it's always been the same or up.

And had you ever had cancer before in your life?

No, no.

Has anyone in the family ever...?

Well, my XXXXXXXXX, she had cancer in the XXXXXXXXXX. She died when she was about XXXXXXXXXX, but she got XXXXXXXX years after the diagnosed it, she died in the XXXXXXXXXXXXXX.

And have you thought about her cancer at all in relation to your own?

No, you're always feeling about for wee lumps, but I think in the neck area a lot of it's glandular, you know? But no, my cancer ... I'm not saying I couldn't see me taking cancer, you didn't expect it because, as I say, I've always been lucky throughout my life, I was never off work, I was in insurance up until I was about in my mid 40s, so I've never really had any health problems, and this is how when it comes along you sort of take it a wee bit more so than somebody that's maybe had various problems

throughout their life. But as I say, I actually thought itwas piles I had, and the doctor told me what it was. And even when he told me, he said it's a major operation you're going in for, and you didn't feel as if you were upset, you just said well, I know Mr McKenzie from previous years and he's well respected up there, and you say well, if he's looking after you, good enough. Just the same as Dr XXXXX, Dr XXXXX's been very good. But my own doctor, Dr XXXXXXXXX, I think he worked in here for five years, and he told me the last time I spoke to him .. he said 'you're in good hands in there, they'll look after you'. So I've no complaints about the treatment or how they've treated me.

And apart from your mother, has anyone else in the family ever had cancer?

No.

And in terms of your household at home, is it you and your wife?

Me and my XXXXXXXXXXXXXXXXXXXXXXXXXXXXXX are married and settled down themselves. I'm fortunate in the position now where I haven't worked for six years, as I say, XXXXXXXXXXXXXXXXXX trades you've got all this redundancy carry on and so forth, and then I had bother with my blood pressure and back trouble, which is sore today. That kept me from work, but fortunately at home you don't owe anything, you've got your own house and it's paid for, so it's not as if you were working with young kids to bring up and you're worried about how you're going to get by, you know? That takes the pressure off you.

And what did you work as before?

XXXXXXXXXXXXXXXXX. The way things went in the eighties with the Conservatives in, Thatcher etc., you were hitting a situation in our trade where you were too old if you were forty, believe it or not. A lot of places just closed down, and you just felt it was going on too long. Now this Government that's in now, they're talking of doing the opposite of what Thatcher done, getting people started again.

What was the company that you worked for?

Oh, various, umpteen over the years.

What was the last one that you worked for?

The last one I worked for as XXXXXXXXXXXXXXXXXX, who are now more or less on the verge of packing in. Before that it was XXXXXXXXXXXXXXXXXX

And in terms of the way it's classified, are you retired?

Classified as retired, uh-huh. Househusband, unemployed, whatever you want.

Do you get Unemployment Benefit?

No.

What I have now is a list of sentences, which haven't been completed, it's just the beginning part and I'd like you to complete them in your own words. There aren't any right or wrong answers, I'm just interested in how you would complete them. So the first one is 'Having cancer means that ....'

I suppose it's a quite outlook; having cancer makes you grateful for your health before you had it, which you're inclined to take for granted. In my case, where I never had much illness, it suddenly strikes home to you that you've got granchildren, and you say to yourself 'how long will I see them for'. But fortunately through this treatment it looks as if it's gone up quite a bit. But at first it hits you hard in as much as you say well, how bad is it, how long have you got. That's why I appreciate what they do here, I dare say there was a time when they couldn't do very much.

The next one is 'When you get cancer, you...'

What, your feelings?

Anything at all, whatever comes into your mind.

Well, I would say when you get cancer you automatically wonder how long you've got to live, how bad it is. If they tell you well, they've managed to sort it out, you obviously feel fine. But I suppose if somebody said well, you've six months to live obviously you'll go into a different mood altogether.

'Cancer is caused by...'

Well, I asked XXXXXXXXX this, the surgeon, and he doesn't know what causes it, no ideas, he reckons it's more in the XXXXXXXXXXworld side than the other side, also what your diet could be. I believe it could also be caused by ... in our trade, if you were doing production work and needed the toilet, you were inclined to say 'well, I'll go in a wee while' which, over the years, you find you shouldn't have done. Maybe this has something to do with it, I don't know.

The next one is 'Cancer is....'

You could put down a lot of things. I don't think anybody knows what cancer really is, I think it's to do with a lot of things. I can go back thirty years, you hardly ever mentioned the word, now it seems to be the word that covers whatever illness.

'When I think of cancer I think of...'

Well, as I say, it could be the previous answers there, when you think of cancer you think of how long you have, how the treatment's going to work, if it's going to be successful or whatever.

'People who get cancer....'

People who get cancer ... it's a strange thing. I've a friend there who XXXXXXXXXXXXXXXX and he didn't have cancer, it was XXXXXXXXXXXXXX in the head he took, and his life was just cut short ... it's been about six months now he died, and he worked hard for his business over thirty years, and then you go to the street corners and you see these characters hanging about, and you say well, how do they not get cancer? But maybe they've got it for all I know. You don't know.

'Before I developed cancer I thought...'

Before you develop cancer you obviously thought there was a possibility you would have some form of cancer, because I think nowadays everybody's got cancer, it's just a case of stamping it away. My own XXXXXXXXXXXXXX, for example, he was fine and looking forward to his retirement, and he fell down the stairs, and within a matter of a few weeks he was in hospital with cancer. You get the impression that it's just even something that triggers it.

'Before I developed cancer I thought that cancer.....'

Thought it was the world's biggest pest. Even worse than traffic wardens!

My cancer was caused by...

Oh I don't know. I've tried to backtrack ... one thing I will say is when I worked with XXXXXXXXXXXXXX we used to do rolls, now these rolls weighed between ten and fifty tonnes in your machine, and we used to bring these lads in for ultrasonic testing, and they sprayed it with a purple dye so that once you machined them they spread out this dye to show up any cracks. Now very often you'd be standing where they were spraying, so I sometimes wonder if it wasn't maybe triggered by the fact that you were breathing

in stuff you shouldn't have been breathing in. Because I remember not long after I started there, I started with thrush in my mouth, a thing I'd never had before. But there again, there's people worked in there for years ... it's just a thing, it's hard to backtrack.

'Cancer treatments are....'

I would say cancer treatments as far as I'm concerned have been no great problem. The people that I've dealt with have been very helpful and good, so you can't say anything about that; in fact, you're grateful for it.

'The main effect of cancer on my life is....'

As I said before, the main effect is when you sit down and say to yourself 'well, I've got this, will I see ...' - just for an example, the lad in XXXXXX when I was in, he came in and he said to me 'you sit here wondering if you're going to see the millennium, if you're going to see your grandkids grow up'. Unfortunately he died round about the end of the year there. So this is obviously on your mind. If you're fit and healthy and you're diving about doing this that and the next thing, you don't think of any of it. It's only when it hits you.

And what impact would you say that has on how you feel in yourself?

Well, it's never really bothered me because I've never looked upon it as cancer. I've been lucky enough in the fact that I've managed to get about, out walking and things like that, I've never suffered hair loss where you're embarrassed to go out, I would say it hasn't really sunk in, no.

The next thing is 'As a person I am....'

Well, Dr XXXXX said to me, and Dr XXXXX too when I first seen her, said 'you're coming in for treatment - if you don't want it, it's up to you', but you feel that well, these people are here to help me, so do what you're asked,and I think this is what you've got to do. If they say eight courses it's eight courses, if they say twelve courses it's twelve courses. There's no point in me turning around and saying 'I don't think I need anything', you know?

'When I think about how I feel about myself I'd say I feel....'

I would say I feel much the same as I did before I had the cancer, apart from the tiredness. But there again you felt tired too before the cancer, but you didn't feel as tired as you do now. I could sit there and inside half an hour you'd

be dozing.

The last sentence is 'When I think about other people in relation to my cancer, I think.....'

Depending on how far the cancer has gone .. I think myself lucky, to be quite honest. I know a lad who's in Airdrie Hospice just now, and a year and a half ago he was fresh-faced, full of life, working, and now he's just got a limited time. When you see people like that ... even in F3 when I first came in, you see people who've had operations, and you say 'well, there but for the grace of God go I' for want of a better statement. But that's basically what you think, you think you've been lucky, or fortunate.

Is there anything else you think it would be helpful for me to know in terms of your experiences so far?

I don't think so, no. Just the fact that it brings home to you the fact that you've had an operation which was a big operation, you were looking forward to the surgeon saying 'you've had your operation, go home and everything's okay'. But when they come in and tell you you've got cancer .. I would say it was more a downer for my wife than it was for me. But I've looked on it from when I was told I had cancer .. I've looked upon it as a sort of way where you would try your best for yourself, really. I dare say there's some people maybe if they're on their own will start thinking things and all the rest of it, which anybody can do. But I think you've got to be positive and be active.

LIFE REVIEW

++
+++ ON-LINE DOCUMENT: 1001-1052215
* No Header
++
[1001-1052215 : 204 - 209]
At the moment not being out doing work, sitting about the house all the time, you start getting bored with just sitting about, you can't go back out to work right away because you know you're not fit enough yet. If you've been working all your life it's a hard time to stop and just say you're not doing any more.

how

++
+++ ON-LINE DOCUMENT: 1005-736823
* No Header
++
[1005-736823 : 185 - 190]
problem. Also, I think you assess your life, and you think no, I've had a good life up to now, maybe I have to do things a different way, but there are things I want to do, and hopefully if my husband keeps well, we're going to do. You've got to look to yourself and decide what's for you. The way I feel so far, I feel well, and God willing

Cancer makes you look at life differently

++
+++ ON-LINE DOCUMENT: 1013-1020820
* No Header
++
[1013-1020820 : 64 - 66]
'where can I meet you, where's best for you?'. You start to feel like some ancient grandparent who's very fragile and could break at any moment. I do have to be careful to

++
+++ ON-LINE DOCUMENT: 1014-1037591
* No Header
++
[1014-1037591 : 417 - 419]
We were planning a retirement. The day before we had 120 people coming to celebrate our silver wedding, we found out it was malignant.

life plans have been changed

++
+++ ON-LINE DOCUMENT: 1023-1144231
* No Header
++
[1023-1144231 : 233 - 238]
I suppose it's a quite outlook; having cancer makes you grateful for your health before you had it, which you're inclined to take for granted. In my case, where I never had much illness, it suddenly strikes home to you that you've got granchildren, and you say to yourself 'how long will I see them for'. But fortunately through this treatment it
...
[1023-1144231 : 315 - 315]
Oh I don't know. I've tried to backtrack ... one thing I will

++
+++ ON-LINE DOCUMENT: 1024-1151415
* No Header
++
[1024-1151415 : 46 - 54]
Probably the outlook - your outlook on life changes somewhat. You think well, today I'm here, we live for today. I tend not to think about the future because you don't know what you've got, so you just live day to day. As such, life becomes a lot easier.
...
[1024-1151415 : 54 - 56]

means that I live for today

I was pretty easy-going before the event, but now ... it's so simple, life now. I find it a lot easier to cope with.

++
+++ ON-LINE DOCUMENT: 1033-171495
* No Header
++
[1033-171495 : 135 - 137]
'People who get cancer...'

Have to take stock of their lives.

++
+++ ON-LINE DOCUMENT: 1034-1037691 text
* No Header
++
[1034-1037691 text : 225 - 227]
I'm dreaming about people I've never seen since school. But it's so real, people are so real in my dreams now, whereas before it was never clear. My brother died there,

++
+++ ON-LINE DOCUMENT: 1035-1160412
* No Header
++
[1035-1160412 : 93 - 99]

Oh yes, I definitely do. Also the fertility side of things as well, not just regarding the chemotherapy but the hormones because obviously I'm post-menopausal just now and will be for the next five years, and that takes me up to 33. It's not a sure-fire thing that it'll revert back anyway, so I don't know if I'll ever have children.

I've been questioning my plans for life.

...
[1035-1160412 : 207 - 210]
Yes, I'm bitter, but it's more towards myself, that I should know better. It wouldn't have changed the diagnosis, but it might have stopped it having spread. Obviously that was almost a year, so I could have stopped the spread.
...
[1035-1160412 : 305 - 309]
flap was taken. There is a lot of scarring, and I think also you decide what's important - I was quite a career person before and now it doesn't bother me at all. I was always wanting to go up a grade, now I just want to go in and do my job and not really get up the ladder.

++
+++ ON-LINE DOCUMENT: PatientNotesWard7A
* No Header
++
[PatientNotesWard7A : 20 - 20]
Patient has been reflecting upon his relationship with his father and how there are things which he never said to him when he was alive. He has also noted the similarity in recent years between his father and himself - particularly with regard to interests.

(M) Prod me to review my life

++
+++ ON-LINE DOCUMENT: t1523b95.txt
* No Header
++
[t1523b95.txt : 104 - 107]
Well, I do think more about my past and the things that have happened, but things that I would have forgotten about, probably. When I was younger, with my family, doing things. In the future, what I find is I've been going

think about my life before cancer.

...
[t1523b95.txt : 330 - 340]
They're quite good ones, actually. My father died when I

was in my early 20s, but I go right back to when I was younger and how I felt then, and I try to think how was I when my mind was free of cancer, before this happened? What sort of thoughts did I have? And they were different then, but I can't put my mind back to the way I thought about things, but I certainly think more rationally, and I don't suffer fools gladly now, and I seem to be able to sort problems out very quickly by cutting off the rubbish round the edges.

++
+++ ON-LINE DOCUMENT: t1525a95.txt
* No Header
++
[t1525a95.txt : 82 - 86]
effect. I find myself re-living my life again. Not that I would want to change things, but I have regrets and I have remorses, and sometimes I think there are unfulfilled ambitions - all the things I'd have liked to have done that I'll never do. Some days I can accept that, some days I

about my unfulfilled ambitions

...
[t1525a95.txt : 111 - 113]
No they're not, they're disturbing. But sometimes I can be sitting and I think back to happier times, and it gives me a lift. I can pick out certain instances, dates, occasions
...
[t1525a95.txt : 119 - 123]
Very, very much so. In fact, we talked about things on a daily basis that we'd forgotten about for a long time. People and places and occasions. My brother comes in for two hours every day and him and I go back to the past a lot. That cheers me up.

making me remorseful about past events

++
+++ ON-LINE DOCUMENT: t1526a95.txt
* No Header
++
[t1526a95.txt : 209 - 211]
Re-appraising life. If you think you're going to lose your life then you begin to think about what you're here for and what you're trying to achieve.

cancer research campaign

UNIVERSITY of GLASGOW

CRC Fellow in Psychosocial Oncology
Dr Craig A White, ClinPsyD AFBPsS C Psychol

CW/PS

23rd February 2000

Mrs Z. Wight
Director
CCPS
Strathdoon House
50 Racecourse Road
Ayr
KA7 2UZ

Dear Zena

Development of a Measure of Core Cancer Related Beliefs and Interpretations

As you know, I am currently engaged in research into cognitive aspects of psychosocial adjustment to cancer and cancer treatments. This involves the development of a measure of generic beliefs (ie not site or treatment specific) associated with common cancer experiences. I have attached a draft of the Core Cancer Meanings Measure in the hope that you might be able to offer some initial feedback on the content and structure of the measure.

This measure was developed from the themes reflected in the transcripts of interviews I conducted with 60 cancer patients with a range of tumours and cancer illness experiences. The measure aims to assess the core beliefs at the heart of what it means to have cancer and although it is likely that the measure will relate to constructs such as cognitive coping style, cancer coping self efficacy and distress, the measure is not designed to assess these variables. I will soon embark upon a phase of field testing of the measure. This will be followed by studies aimed at validation of the measure and study of cognitive contributors to psychosocial adjustment.

Please feel free to make suggestions regarding what you feel may be glaring omissions with regard to item content. I will also be grateful for any further comments that you might wish to make at this stage in the development of the measure. I am most grateful to you for considering this request.

With kind regards,

Yours sincerely

Craig A. White
CRC Fellow in Psychosocial Oncology

Enc.

DEPARTMENT OF PSYCHOLOGICAL MEDICINE
Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH
Telephone: 0141-211 3902 *Fax:* 0141-357 4899 *Email:* craig.white@clinmed.gla.ac.uk

ITEM NUMBER	BELIEFS	*DO NOT AGREE*	*AGREE SLIGHTLY*	*AGREE MODERATELY*	*AGREE VERY MUCH*
1	My cancer philosophy is 'live for today'	0	1	2	3
2	Cancer rules my life	0	1	2	3
3	It is not fair that I developed cancer	0	1	2	3
4	I am going to die as a result of my cancer	0	1	2	3
5	Cancer is a challenge	0	1	2	3
6	People are there for me no matter what happens with my cancer	0	1	2	3
7	My world has fallen apart because of cancer	0	1	2	3
8	Cancer interferes with living my life	0	1	2	3
9	I am conscious of cancer all of the time	0	1	2	3
10	The things I had planned for my life are no longer options	0	1	2	3
11	My thoughts about cancer are out of control	0	1	2	3
12	My faith in God will see me through my cancer	0	1	2	3
13	Cancer is not as bad as it is made out to be	0	1	2	3
14	Cancer has changed every aspect of my life	0	1	2	3
15	I wonder if my cancer has spread	0	1	2	3
16	Everything about cancer is bad news	0	1	2	3
17	Other people are nosey when it comes to my cancer	0	1	2	3
18	My life has been shattered because of cancer	0	1	2	3
19	There is no escape from cancer	0	1	2	3
20	I accept that I have cancer	0	1	2	3

ITEM NUMBER	BELIEFS	DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
21	I know that I will be cured of my cancer	0	1	2	3
22	I have no control over any aspect of my cancer experiences	0	1	2	3
23	Cancer is a death sentence	0	1	2	3
24	There are some good things about having cancer	0	1	2	3
25	Knowing that I am in good hands helps me to get through my cancer experiences	0	1	2	3
26	Other people do not understand what it is like to have cancer	0	1	2	3
27	Everything about cancer is negative	0	1	2	3
28	It is best to leave all cancer decisions to the doctors and nurses	0	1	2	3
29	I appreciate life more because of cancer	0	1	2	3
30	I must have done something negative in my life to have developed cancer	0	1	2	3
31	Cancer is at the root of all my problems	0	1	2	3
32	I don't have cancer	0	1	2	3
33	My family will be left without me	0	1	2	3
34	Luck will determine what will happen to my cancer	0	1	2	3
35	Others I know with cancer have inspired me	0	1	2	3
36	Staff in the cancer centre are there to help me in whatever way they can	0	1	2	3
37	My world has collapsed around me because of cancer	0	1	2	3
38	Other people's reactions to my cancer give me hope	0	1	2	3
39	I have lost control of my life because of cancer	0	1	2	3
40	Having cancer restricts my life	0	1	2	3

CCMM-peer

ITEM NUMBER	BELIEFS	DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
41	There are worse things that could have happened to me than having cancer	0	1	2	3
42	Cancer makes you focus on what really matters	0	1	2	3
43	I cannot escape reminders that I have cancer	0	1	2	3
44	Cancer doctors and nurses are there to help me in whatever way they can	0	1	2	3
45	All I see around me is suffering because of cancer	0	1	2	3
46	Cancer should not have happened to me	0	1	2	3
47	Cancer doctors don't really care about what happens to me	0	1	2	3
48	I don't know what is happening with my cancer care	0	1	2	3
49	My life will never be the same again because of cancer	0	1	2	3
50	There is so much about cancer that I do not understand	0	1	2	3
51	I have lost my independence as a result of cancer	0	1	2	3
52	I am a completely different person because of cancer	0	1	2	3
53	I have no control over the course of my cancer	0	1	2	3
54	Other belief: _____	0	1	2	3
55	Other belief: _____	0	1	2	3
56	Other belief: _____	0	1	2	3
57	Other belief: _____	0	1	2	3

Appendix 11
Protocol for Field Testing Phase

DEVELOPMENT OF A COGNITIVE MODEL OF PSYCHOSOCIAL ADJUSTMENT TO CANCER
CORE CANCER MEANINGS MEASURE
FIELD TESTING

1. Begin the field testing by explaining the aim of the interview:

This questionnaire asks you about your thoughts as they relate to your experiences of cancer. I would like you to read it and complete it so that I can then ask you some questions about what you have written and your comments on the questionnaire. This will be helpful for the future development of the questionnaire. I will be asking you about things like what aspects of your experiences you think it assesses; how you have understood the items and any suggestions that you might have for changing or rephrasing items for the questionnaire. Please feel free to ask me any questions that might occur to you as you complete the questionnaire.

2. Give the patient the questionnaire to complete

If the patient asks questions during the completion of the questionnaire, note down whether these refer to a specific item and what the question is.

COMMENTS/ OBSERVATIONS MADE DURING COMPLETION (ensure that if this refers to an item this is written in brackets)

_____

_____

_____

_____

_____

_____

_____

3. When the patient has completed the questionnaire, provide an explanation for the next phase of the field testing.

Now I will select some of the items that you have completed and ask you about what you have written. Then I will ask you about what you think the questionnaire was assessing and your feedback on what you thought about it in general.

4. **Choose 3 items endorsed by the patient as ones with which they "Agree Very Much". Ask the patient to elaborate on their responses to each question:**

I see that you indicated that you Agree Very Much with the belief that _____ Tell me your experiences relating to this. What led you to answer in this way ?

Supplementary questions:
What makes you say this about what cancer means to you ?
What makes you say this about how you think about cancer ?
What led you to answer in that way ?
What led you to choose this answer and not one of the others ?

Agree Very Much

Item Number	Patient Elaboration

Other Comments

_____

_____

_____

5. **Repeat this for 3 items endorsed for each of the possible responses to level of agreement on the questionnaire.**

I see that you indicated that you Agree Moderately with the belief that _____ Tell me your experiences relating to this. What led you to answer in this way ?

Agree Moderately

Item Number	Patient Elaboration

Other Comments

_____

_____

_____

_____

Agree Slightly

Item Number	Patient Elaboration

Other Comments

_____

_____

_____

_____

Do Not Agree

Item Number	Patient Elaboration

Other Comments

There are some items within the questionnaire which require participant feedback to assist with decisions about inclusion of items in subsequent versions of the measure. These relate to issues such as readability, understanding of items and construct validity of the measure.

One of the items from the questionnaire was "My cancer philosophy is "live for today"" tell me what you understood this to mean ?

_____

_____

_____

_____

The questionnaire included the following: "My world has fallen apart because of cancer"; "My life has been shattered because of cancer" and "My world has collapsed around me because of cancer". Do you think that these items are different ? If so, in what way so you see them as being different ?

_____

_____

_____

_____

The questionnaire had an item "Cancer interferes with living my life". What sorts of things did you think this was asking you about ?

_____

_____

_____

_____

The questionnaire had an item "Cancer has changed every aspect of my life" What did you think that it mean by "every aspect"?

The questionnaire had the item "I wonder if my cancer has spread" How did you see this as relating to your own cancer experiences at the moment ?

The questionnaire had an item "Cancer is a death sentence" How did you feel about having to respond to this question ?

The questionnaire included the item "There are some good things about having cancer" Now check if patient endorsed this as an agree response. For these respondents, ask: What things did you have in my mind when you answered this question ? For remaining respondents: What do you think that this question meant by "some good things"?

The questionnaire included the item □Knowing that I am good hands helps me to get through my cancer experiences□ Now check if patient endorsed this as an agree response. For these respondents, ask: Who did you have in mind when you were thinking of the words □□ in good hands□ ? For remaining respondents: Who do you think this question was referring to by using the phrase □.. in good hands□ ?

Determine patient response for item 32 □I don□t have cancer□ What do you think this question was designed to assess ? Tell me why you answered it the way that you did.

7. **Participants should now be invited to comment on the questionnaire in general. Provide the opportunity for them to highlight specific items that caused difficulty and/or upon which they would wish to comment.**

What did you think that questionnaire was measuring ?

Were there any items that were difficult to understand ? Which ones ?
How might you have rephrased this ?

Were there any items of the questionnaire which were annoying or upsetting ? Which ones ?

Were there questions which you found were irrelevant ?

Can you think of additional beliefs that are relevant for you but are not included in the questionnaire ?

Do you have any other comments about the questionnaire ?

CAW

14.02.00 (revised 08.05.00)

Appendix 12
Core Cancer Meanings Measure for Field Testing (55 item Version)

CONFIDENTIAL
Your Thoughts about Cancer

Having cancer means different things to different people. This questionnaire contains a range of thoughts that people might have about their cancer. The purpose is for you to identify the thoughts that you hold about your cancer.

Please read each item carefully and rate how much you agree with each thought by circling a number to the right of the item.

Each number in the right hand column refers to a different level of agreement with each thought:

0 indicates that you DO NOT AGREE with the thought
1 indicates that you AGREE SLIGHTLY with the thought
2 indicates that you AGREE MODERATELY with the thought
3 indicates that you AGREE VERY MUCH with the thought

ITEM NUMBER		DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
87	Cancer is a serious illness	0	1	2	3

↑ Read each thought and then decide how much you agree with it

↑ Circle a number to indicate how much you agree with each thought

Thank you for taking the time to complete this questionnaire.
If you have any questions then please contact Dr Craig White
Clinical Research Fellow in Psychosocial Oncology on 0141 211 3902

Core Cancer Meanings Measure

ITEM NUMBER		DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
1	My cancer philosophy is □live for today□	0	1	2	3
2	Cancer rules my life	0	1	2	3
3	It is not fair that I developed cancer	0	1	2	3
4	I don□t plan for the future because of my cancer	0	1	2	3
5	Cancer is a challenge	0	1	2	3
6	People are there for me no matter what happens with my cancer	0	1	2	3
7	My world has fallen apart because of my cancer	0	1	2	3
8	Cancer interferes with living my life	0	1	2	3
9	I think about my cancer all of the time	0	1	2	3
10	The things I had planned for my life are no longer options	0	1	2	3
11	My thoughts about cancer are out of control	0	1	2	3
12	My faith in God will see me through my cancer	0	1	2	3
13	Cancer is not as bad as it is made out to be	0	1	2	3
14	Cancer has changed every aspect of my life	0	1	2	3
15	I wonder if my cancer has spread	0	1	2	3
16	Everything about cancer is bad news	0	1	2	3
17	Other people pity me because I have cancer	0	1	2	3
18	My life has been shattered because of cancer	0	1	2	3
19	There is no escape from cancer	0	1	2	3
20	I accept that I have cancer	0	1	2	3

ITEM NUMBER		DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
21	I know that I will be cured of my cancer	0	1	2	3
22	I have no control over any aspect of my cancer experiences	0	1	2	3
23	Cancer is a death sentence	0	1	2	3
24	There are some good things about having cancer	0	1	2	3
25	Knowing that I am in good hands helps me to get through my cancer experience	0	1	2	3
26	Other people do not understand what it is like to have cancer	0	1	2	3
27	Everything about cancer is negative	0	1	2	3
28	It is best to leave all cancer decisions to the doctors and nurses	0	1	2	3
29	I appreciate life more because of cancer	0	1	2	3
30	I must have done something wrong in my life to have developed cancer	0	1	2	3
31	Cancer is at the root of all my problems	0	1	2	3
32	I don□t have cancer	0	1	2	3
33	Other people exaggerate the seriousness of my cancer	0	1	2	3
34	Luck will determine what will happen to my cancer	0	1	2	3
35	Others I know with cancer have inspired me	0	1	2	3
36	I am better off than most people with cancer	0	1	2	3
37	My world has collapsed around me because of cancer	0	1	2	3
38	Other people□s reactions to my cancer give me hope	0	1	2	3
39	I have lost control of my life because of cancer	0	1	2	3
40	Having cancer restricts my life	0	1	2	3

ITEM NUMBER		DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
41	There are worse things that could have happened to me than having cancer	0	1	2	3
42	Cancer makes you focus on what really matters	0	1	2	3
43	I cannot escape reminders that I have cancer	0	1	2	3
44	Cancer doctors and nurses are there to help me in whatever way they can	0	1	2	3
45	All I see around me is suffering because of cancer	0	1	2	3
46	Cancer should not have happened to me	0	1	2	3
47	Cancer doctors don□t really care what happens to me	0	1	2	3
48	I don□t know what is happening with my cancer care	0	1	2	3
49	There is so much about my cancer experience that I do not understand	0	1	2	3
50	I have lost my independence because of my cancer	0	1	2	3
51	I am a completely different person because of my cancer	0	1	2	3
52	I have some control over the course of my cancer	0	1	2	3
53	Other people□s reactions to my cancer make me pessimistic	0	1	2	3
54	I have no future because of cancer	0	1	2	3
55	I keep thinking that my cancer might come back	0	1	2	3
56	Other thought:	0	1	2	3
57	Other thought:	0	1	2	3
58	Other thought:	0	1	2	3
59	Other thought:	0	1	2	3
60	Other thought:	0	1	2	3

Appendix 13
Full Results of Information Obtained During Field Testing

General Comments and Observations on Administration

Comment Number	Comment/ Observations
1	Patient looking sideways at the response stems
2	More deliberation over potential double negative at Item 22
3	Asked □is this based on how I feel at this moment in time □?
4	Patient looking sideways at the response stems
5	Patient placing left hand down the side of the page to follow items
6	Patient turned 2 pages at once
7	Asked if had to be completed in general or personally (Item 23)
8	After reading a few items patient said □I will make a special note of the ones that I want to qualify in some way□
9	Noted during interview that problems with understanding the words □exaggerate□and □reactions□
10	Problems with following items over to the 0 1 2 3 responses (as well as orientation of stems)
11	Patient commented that there were more negative items than positive on the questionnaire
12	Items 22 - later changes regarding initial response
13	Item 21 - know is rather a strong word - I am optimistic that it will be
14	I accept that I HAD it, I accept that I may have it still
15	What about this item here, is this just an example ?
16	Item 6 - does that mean my family and friends ?
17	Now □philosophy□what does that mean ? Now □live for today□what does that mean ? Looking at stems sideways
18	Mentioned □I focus on my family. I always know they will be there for each other□
19	Note that missed out 23,24,27,30,31,33 and 35 first time round

Patient Elaboration on Specific Items

Item No.	Item	Comment(s)
1	My cancer philosophy is □live for today□	• Knows that no cure and therefore lives for today and puts in the hands of God • Since the diagnosis I have been doing things that I have never done before and wanted to do
2	Cancer rules my life	• It does not. I have accepted it an am getting on with my life. It has not stopped me in any way. • All the tablets and treatments. You need to make adjustments to your private life and arrangements • Having to come into hospital □ slightly • No not at all • Absolutely not
3	It is not fair that I developed cancer	• I am not a smoker and I rarely drink. • It is silly to say □it has nothing to do with fairness. It is not fair that anyone gets cancer. • If it wasn□t me it would be someone else. It is not fair and unfair, rather me than my family. • I don□t think that fairness comes into it • Well sometimes I think that it is not fair, I have never done anyone any harm, I have worked, why God now ? • I am saying that because I have never been ill. Why me - you see people with drink and drugs and I suppose that is a wee bit selfish
4	I don□t plan for the future because of my cancer	• I feel that having treatment and life is revolving around that □I have no future plans • I made a mistake in answering that. Yes when I was told at first. • Basically a holiday

5	Cancer is a challenge	• Cancer treatment is a challenge. • I found the chemotherapy quite hard and had to change my job and child care arrangements. • I am always fighting, it is ongoing • It is a challenge to the medical profession. Generally it is a disease. • It is a challenge to your whole life □it is completely out of the blue • I am not too sure why • I think from the point of view of how you approach the fact that you have cancer - it is a challenge to mental processes. You can become obsessed or ignore it and get on with everyday living. If cancer doesn□t kill you then something else will, irrespective of the Human Genome Project • I don□t feel it is a challenge, I feel it is out of my hands • It is a challenge to keep going at times. It can be a challenge to face people. • If you□ve got it it is a challenge. You fight it and mentally think positive.

6	People are there for me no matter what happens to my cancer	• 1. I have a lot of family support □positive thoughts which give me confidence
		  • My family are quite supportive if I am feeling down and my mum does the washing
		  • Everyone has been quite supportive □neighbours and friends
		  • My husband died last year. Sister stays with me and makes sure that I am all right. She drives me around and takes me out.
		  • My parents and wife are supportive and my sisters. Because my sister has had cancer they see my

		coming here as helping me make a recovery • I do feel that - I have had strong support from my family
7	My world has fallen apart because of cancer	• SPECIFIC PROMPT LATER
8	Cancer interferes with living my life	• Going to but a new shirt or a new suit. It interferes with holiday plans. • I have to depend on other people whereas before I was independent • Coming to the Beatson • It doesn't interfere at all
9	I think about my cancer all of the time	• Definitely not • When I waken up and look out it is a nice day,then I think that I have cancer. It is with you all of the time. • 90%of the time I think that it is never going to recur. If I thought about it all of the time then I would not get on with life. • It is on my mind most of the time –when I am planning things I think whether I will be feeling good • No I certainly don't. I don't think of it any of the time.
10	The things that I had planned for my life are no longer options	• I know that life is shorter. I cannot plan ahead and say I will do this or this in 5 years time
11	My thoughts about cancer are out of control	• I can think about it logically. The only thing is that I am terminally ill and I don't want to be apart from my family • Treatment has gone as far as it can. I can't see a future –I am off the family Christmas card list. • They are not out of control. I don't think of funerals. • They are not
12	My faith in God will see me through my cancer	• I don't believe in God • I have conflicting thoughts, if there is a God then why did he let me take it. • I am not very religious. I believe there is a God and something is looking after me

		• Whether Christian or not, whatever happens in life may be this is the only time that you turn to God and ask what you have done wrong in life that this should happen
13	Cancer is not as bad as it is made out to be	• Although in liver, lungs and had a stomach operation, it is not as bad as it could be • I could never have imagined what is has been like taboo and fear of the unknown • People take cancer and think that they will be dead. I don't agree with that attitude. • When I was told that I had breast cancer I thought that I was going to die. I didn't realise that I could be cured. • I have not had the pain of cancer (except for the pain before the operation). This could change. • Some cancers are not as bad as they are made out to be. It can be bad. • Looking at breast cancer - things are hugely better. 15 years ago it was almost a death toll. • There are so many different cancers. A lot are successful. My brother has had throat and skin cancer - he has not got them now.
14	Cancer has changed every aspect of my life	• Made me very aware of how very precious life is and to get the most of the life that I have • Whole aspect changes there is no restriction in what I am going to do • Thinking about my family's future. I don't do some of the things that I used to do.
15	I wonder if my cancer has spread	• You don't know if it is going to be completely away whatever time the doctors give you is appreciated • I don't feel ill, before the surgery I was sick. • Naturally I would not be at the Beatson if there was not

		the possibility of spread now or in the future
16	Everything about cancer is bad news	• I was given 4 months to live □ in 1997 • At first my world collapsed and I didn□t see a future. It is slightly like that now I see a wee bit of a future. • It is such an emotive subject □ an emotive word. • I don□t think that there is anything good about cancer • It is not. There was good news in the papers recently • Would say that everything about cancer is bad. There is progress and ways to counteract it . Ways that can help. At the end of the day someone will cure it.
17	Other people pity me because I have cancer	• People think the same sort of thing □Christ he is going to die (not everybody) • They don□t exactly pity you - they refer to someone who has it and give you a word of encouragement (Note - stem contradicted)
18	My life has been shattered because of cancer	• It was shock and total horror, the way that it was put to me did not help
19	There is no escape from cancer	• If you□ve got it you□ve got it and that□s it • Not everybody gets cancer □I don□t know why some do and some don□t • According to the statistics everyone has got it until it suddenly breaks out • Since 40%of the population will have it at one time or the other, you cannot escape and inherited gene , carcinogenic stuff in the air or being a heavy smoker
20	I accept that I have cancer	• It is the way that this one is phrased. At this stage it is an unknown quantity as this course has finished • I agree very much certainly
21	I know that I will be cured of my cancer	• It recurs and there is a shortened span of life. • No □I am quite well in control

		of the situation and not letting it take over my life. • It is not a certainty is it □ tumours can recur after a few years • I am sure that Prof George will see me through this • The surgeon said that it is all away so I feel as if I have not got cancer
22	I have no control over any aspects of my cancer experiences	•
23	Cancer is a death sentence	• SPECIFIC PROMPT LATER
24	There are some good things about having cancer	• It brings things into perspective • Once people knew, people that I thought were cold and standoffish showed a great depth of understanding • Nothing possibly of any good with cancer
25	Knowing that I am in good hands helps me get through my cancer experiences	• I have good doctors and nurses. Sometimes getting information is a problem
26	Other people do not understand what it is like to have cancer	• The only people that have it are those with it. It speaks for itself. They are easier to talk to. • It is not necessarily always bad news • My sister in law does not know what to say □my wife tells her to treat me normally • I don□t think that they really understand. (TV medic example)
27	Everything about cancer is negative	• I have made friends and am closer to my family • There are so many cures □so many people get cured, you have to look on the positive side • What does negative mean ?I am not sure
28	It is best to leave all cancer decisions to the doctors and nurses	• I don□t agree to leave it all to them □no-one likes giving up control of their body. • They have more experience and have seen many patients. • They give me some options regarding the treatment, some input. If I said no then that would be it.

		• They know best don□t they ? • I am too ignorant about cancer myself to think that I could do anything about it. It is a doctors profession and out of confidence for them • Maybe I should have put a two. They always say that patients have options but does the patient have the final say ? • That□s their profession - the patient knows absolutely nothing
29	I appreciate life more because of cancer	• My life has always been the same. Cancer has not stopped it in any way • I have always appreciated life □it is a gift. • It makes you appreciate the things that you have got and how you don□t think about it until you think you are going to lose them • Something you think that is not going to happen and makes you appreciate things • I don□t feel that the cancer I had has made any difference to my life • Yes I think it does. It is the fear initially that you are going to die and the thought get out there and do things.
30	I must have done something wrong in my life to have developed cancer	• It is just the luck of the draw sort of thing □some have never smoked some have smoked. • No. I can□t work out where it has come from. It is just your luck. The smartest people in the world cannot work it out.
31	Cancer is at the root of all my problems	• Cancer is not at the root of all my problems.
32	I don□t have cancer	• The surgeon said that it was all away and so I don□t think I have cancer • I don□t know if I have it. That□s like the one that I accept that I have cancer
33	Other people exaggerate the seriousness of my cancer	• When they see how well I have been doing since Treatment, confidence and

		colour in my cheeks • As soon as people found out they thought it was a death sentence • Mainly people to whom the word cancer terrifies them, people with past experience of others living and dying with cancer are no problem. It is casual acquaintances. • They do, they definitely do. Certain people all they want to tell you about is people who have died. You never hear good news.
34	Luck will determine what will happen to my cancer	• Luck has nothing to do with it • I don□ think that it has anything to do with luck • I don□ believe in luck, I don□ believe in it at all • If I am lucky I will escape return the other or elsewhere • I don□ agree. I don□ think that luck comes into it.
35	Others I know with cancer have inspired me	• When you look at TV □lan Dury and Helen Rollason. They inspire you. • One other patient was □very up□ prior to chemotherapy. I was keen to speak to her. This made me optimistic and I was encouraged • Some are positive and some are doom and gloom. • A couple of people I know have told me what to expect. I put moderately as I sometimes doubt a complete cure. • My wife has cancer 5 years ago and we gave her up for lost. She battled through and is still with us. • People I know of that have come through it. How they have reacted. • I know a lot of people. They just take every day as it comes, it helps me a lot.
36	I am better off than most people with cancer	• I have a lot of support • I am getting the best of treatment, I am pleased, better than anywhere else in

		the world • I have met a lot of people who are worse off than me • Not as bad as others seen in G10. I am still in good health and can do some things with no catastrophic effects • I know a few people with no hair or in a wheelchair. I don't feel ill and have no pain or suffering. • Yes, of course. I see people in the waiting room. I feel that mine was caught early. • Because I would think of cancer of the reproductive organs as very serious (testicle or ovary). Mine is a little spot of lung cancer clear of the airways
37	My world has collapsed around me because of cancer	• I am better off than a lot of people that have cancer.
38	Other people's reaction to my cancer give me hope	• All friends and family accept it and give me hope. They are just there for me • A lot of people have been positive and kind • At the beginning everyone expects you to get better but others reactions have changed • It all has been pretty positive but it is always at the back of my mind • People who have had cancer themselves can give quite a lot of support and hope
39	I have lost control of my life because of cancer	• Because I am trying to look forward "being cured and getting back to normal again
40	Having cancer restricts my life	• It does if I am tired "I can't do the things that I want • Cannot just go out whenever I want to
41	There are worse things that could have happened to me than having cancer	• Cancer is a terrible, terrible " an evil of the 20th century, a scurge • When I look at people coming up here "you wouldn't think I was ill to look at me • In 1972 my 9 year old son was killed by a car outside my house. Nothing can be as bad as that.

		• A car accident, being crippled or being in a wheelchair not being able to do far more things. MS or some sort of severe brain problem. • Who is to say that I will die of cancer. Supposing I decide to go out on my bike - I could get knocked over.
42	Cancer makes you focus on what really matters	• Cancer is not the first thought that enters my head □nothing has changed , though I think about what if it had been worse • It brings things to the forefront of your mind □ family, what matters and the rest of your life, what is important • Most of the time it never enters my mind. It has made no difference to my short or long term planning or attitude to life. • I don□t think about cancer. It doesn□t come into my mind at all • I thought that I better go and make a will which I should have done anyway. Everything sorted out. Just slightly with the things that I have to do.
43	I cannot escape reminders that I have cancer	• I don□t have any reminders of cancer. I am not sure what reminders means. • Out walking the dog and I don□t feel ill • Every newspaper, every time I switch on the TV, it seems to be a conspiracy. These reminders irritate me. • Yes, because I have a colostomy and every time it works I am reminded
44	Cancer doctors and nurses are there to help me in whatever way they can	• They are. They can operate on you and give you wonderful drugs. Nurses to discuss things with.
45	All I see around me is suffering because of cancer	• I see the opposite really
46	Cancer should not have happened to	• I am not a smoker, I do not

	me	drink and I have healthy life. I cannot understand why I got it. • I can't understand how anyone can think that • I feel as if I am young and why at 35 years. I did smoke when I was younger but I was always fit and active. I know about cancer cells - how did the cell come in my body ? I had a good diet • I have a family history - why should it not have happened. Why not, my mother had the same sort of thing
47	Cancer doctors don't really care about what happens to me	• The doctors are very good. • I put the wrong thing down
48	I don't know what is happening with my cancer care	• I feel that at every step the doctors explained what the score is and every eventuality. I was well informed. • I am coming to the end of Treatment and I don't really know what happens now. • I don't really understand what is happening. I was told that there was nothing in my scan but I have had scan □. • I see Prof George so often and he thinks that I am doing very well.
49	There is so much about my cancer experience that I do not understand	• I don't think that I know enough about it
50	I have lost my independence because of cancer	•
51	I am a completely different person because of cancer	• The tablets that I take can control things (sickness and diarrhoea) and if you feel tired you can lie down • I tend to do things more for my self than to run after other people • I have a different nature □I have not got the same patience and am feeling sorry for myself • I am a different and more considerate person, tolerant and I appreciate not as bad off • I am through the op and I

		don□t feel as if I have cancer. I look better now. • No I haven not. It has not made me do anything differently apart from getting a will made.
52	I have some control over the course of my cancer	• Doctors take into consideration your opinion □ you get a chance to put your point of view • Positive thoughts and Treatment has worked so far. I have been living for 5 and a half years, I don□t want to leave my family. • Most recently we have both agreed on treatment decisions • When I was first diagnosed and they said surgery I thought □hang on I will make the decision about the operation□ I said only to carry on if it would make me as fit as I am now (in the long run) • I do as Prof George tells me to do - take my tablets at 8am • They say that if you are positive then you have a better outcome - eat well, live well and get on with life • When I say that I have control it is thoughts, I am not going to lie down to it. I think that I am good for another couple of years.
53	Other people□s reactions to my cancer make me pessimistic	• No not at all. • I just don□t like people meeting me and asking about how the cancer is. I would rather walk on. • People don□t know what to expect. They thought I would be grey. They are glad when they see me that I am not dying. It is a horrible word for everyone.
54	I have no future because of cancer	• I really don□t □the survival rate is only 40% • What future can I look forward to at my age
55	I keep thinking my cancer might	• I don□t keep thinking about it

	come back	but it has crossed my mind. I realised this when I came back for radiotherapy. • Once you have it, it never really leaves you. I believe that it will always come back somewhere else • Again as I say if I didn't keep thinking that and remembering that then I would have said forget it (re the chemotherapy) • It might appear at another spot

Patient Responses to Specifics

One of the items from the questionnaire was □My cancer philosophy is □live for today□□□tell me what you understood this to mean ?

Comment Number	Comment/ Observations
1	Enjoy life and get on the best that you can
2	Probably my opinion about what life is about □I have always lived for today anyway
3	Live one day at a time □you only get one day at a time.
4	Go out and make the most of it. Don□t sit and feel sorry for yourself, just go for it. It is too easy to sit and dwell, life is for living.
5	I do things more for myself, I do what I want to do, rather than someone forcing me into something that I do not want to do. Life is too short.
6	Live today as if you might not be here tomorrow. Live life as normal as possible
7	Not to lie down to it □turn round and make the best of what you have. I am sneaking a few days holidays but can□t turn round and plan what I am doing for the September weekend.
8	Implies that cancer is terminal. It does not need to be terminal. There are slight elements of this regarding planning and outlook for the future.
9	You will not be here tomorrow
10	Just make the most of what you have got
11	That they don□t expect there to be a tomorrow - this is a negative and pessimistic state of mind. I enjoy things as much as possible but not because of this.
12	No - I am not sure
13	I have always just lived for today, you could get knocked down by a bus tomorrow. As a person I am happy go lucky
14	This seems to apply to people whose cancer is terminal. Get the most out of today. I have a few more days to come.
15	Going to get up and live life today, be as full as it possibly can be, not going to waste a minute. No-one knows what is going to happen.
16	What does philosophy mean ?What does live for today mean ?

The questionnaire included the following: □My world has fallen apart because of cancer□; □My life has been shattered because of cancer□and □My world has collapsed around me because of cancer□ Do you think that these items are different ?If so, in what way so you see them as being different ?

Comment Number	Comment/ Observations
1	Yes, I suppose they are but there is a time perspective to take into account
2	They are asking the same thing
3	It is shattering, the shock □there is no other word for it
4	It was shattered initially and as I move on my world has fallen apart. Collapsed would mean completely finished.
5	Same thing
6	Same items
7	These are very similar, along similar lines. I was surprised to see them repeated.
8	This is the same question
9	It is all about the same thing
10	What this is asking about is attitudes and a lack of moral fibre. Long ago I took up the attitude that you should only worry about the things that you can do something about.
11	Well they are the same
12	It depends, in a wide ranging sense they are
13	They all seem extreme
14	They are all probably the same. Life is shattered initially.
15	All the same thing to me

The questionnaire had an item □Cancer interferes with living my life□ What sorts of things did you think this was asking you about ?

Comment Number	Comment/ Observations
1	Being tired □it interferes with visiting
2	They way life was before compared with the way that it is now
3	It only interferes with appointments and cannot work during treatment
4	Stopping from going out and enjoying myself
5	Sex life was the first thing that came to mind
6	Got to think of the treatment first and tend to do things round the treatment I am receiving
7	I am not as fit and I can□t do things that you do □driving and working
8	Generally planning and restricted in what can do or attempt, be active to take mind off matters. I cut the grass twice a week.
9	It depends on the type of cancer and how serious □hospital admissions
10	How it effects day to day life □work

11	How you live your life from day to day
12	This is a bit generalised. It depends on the extent of the cancer and the extent to which it is operable or inoperable and the future prognosis. This is too generalised.
13	Well that it spoiled my life, spoiled me having a life
14	Does it inhibit what sport you do, used to do or whatever, active social life or working ?
15	Nothing comes to mind immediately. Some people fall back on religion.
16	Going out and stopping from mixing. It might stop you if it was a bad cancer, work, sport and bringing up family
17	The everyday activity that they had prior to having it

The questionnaire had an item □Cancer has changed every aspect of my life□ What did you think that it mean by □every aspect□?

Comment Number	Comment/ Observations
1	Probably meaning my outlook on life
2	Depends on other people □it could effect them, they could be morbid and have a different outlook on life
3	Going out and enjoying normal everyday things
4	It does change every aspect □whole emotions and mental attitude to self and to other people
5	Whether it has changed the whole of life □thoughts and attitude
6	Holidays and treatment, all of it
7	I haven□t the same incentive □I lack ambition and I am up the creek
8	That is has taken over life completely
9	Work, house and social life
10	Your whole life
11	Relating to an individuals reaction to their cancer
12	Your life in general
13	Family employment and social
14	It could with someone with brain cancer or lymphoma
15	It has not changed every aspect, I live life as best I can.

The questionnaire had the item □I wonder if my cancer has spread□ How did you see this as relating to your own cancer experiences at the moment ?

Comment Number	Comment/ Observations
1	Well it has spread □to my liver and lungs
2	I think that I am cured, I feel terrific. If it spreads then it is no-ones fault
3	I think that everyone thinks, has it gone somewhere else
4	I am told it has not and I believe them
5	There is always a bit of doubt in my mind. I hope that it is

	gone □a wee bit of doubt
6	I often wonder if it is growing. I know that it has spread from the beginning. From week to week, has it grown or gone to my bones
7	Obviously yes or I would not be here
8	Family are well informed by staff and oncologist involves in discussion. We are not left to wonder and are kept in the picture
9	I don□t know whether it has □they told me it was all away
10	No I don□t think like that
11	I would not be coming to the Beatson for treatment if I did not think that
12	It hasn□t spread. Prof George told me that
13	I worry about that. I worry that it comes back - spread or returns.
14	That is the biggest fear - I wish that there was a magic machine that could tell you. I am living in hope I wish that I could know.
15	I am lead to believe that it does not spread as fast in older people

The questionnaire had an item □Cancer is a death sentence□ How did you feel about having to respond to this question ?

Comment Number	Comment/ Observations
1	Not upset
2	No worse than any other question
3	I think that that is rubbish □I don□t take that in any way at all
4	Didn□t bother me
5	Death does not frighten me □I did not mind
6	I was quite happy to answer the question
7	It is a death sentence for me but I didn□t mind answering it. It is different according to whether you mean generally or specific to me
8	It wasn□t for my wife but it is for me
9	I didn□t bother having to respond to it
10	I was allright with it, not taken a back or shocked
11	It was a bit demoralising I think
12	pretty neutral
13	Its just how you look at it. I am not looking at it like that, it didn□t bother me
14	I think it is dramatised a lot- □the killer disease□ No problem as it is a thing that I have thought about.
15	I didn□t see it. (CW draws attention to on form) For me it depends on type, certainly not for everybody
16	I think 15 years ago it almost was, not so much the case now. Alright.
17	Many ordinary people will think this, I would not say that

The questionnaire included the item □There are some good things about having cancer□ Now check if patient endorsed this as an agree response. For these respondents, ask: What things did you have in my mind when you answered this question ? For remaining respondents: What do you think that this question meant by □.some good things□?

Comment Number	Comment/ Observations
1	Lets you see how others react □they see you in a different light
2	An awareness of how important life is
3	I cannot relate to that in any way
4	Whether you are going to improve and change your lifestyle with new challenges
5	The only thing I can think of is that I tend to do things for myself
6	Meeting people and learning about different treatments, becoming interested. It opens your eyes to others experiences and we are closer as a family.
7	If anything can suggest something favourable then they shouldn□t be involved with research
8	I am not sure what good things □I don□t see any good
9	I don□t know what that they meant by that
10	This is personal to the individual being asked. It may be that some people find faith or religion. Personally I would say that anyone who thought that needs psychiatric treatment.
11	I don□t think there are any good things
12	I have found out that Drs are there for you and are helpful. There is backup a team to help, support and answer questions
13	I imagine that it means that people appreciate the support of friends more
14	You do lead a more full life, are more tolerant and wonder why people get upset by silly things. You appreciate what you have more.
15	What would it make you realise ?People are worse off then yourself

The questionnaire included the item □Knowing that I am in good hands helps me to get through my cancer experiences□ Now check if patient endorsed this as an agree response. For these respondents, ask: Who did you have in mind when you were thinking of the words □□ in good hands□ ? For remaining respondents: Who do you think this question was referring to by using the phrase □.. in good hands□ ?

Comment Number	Comment/ Observations
1	The doctors and nurses and above all God
2	Doctors and nurses at the BOC and Victoria Infirmary
3	Dr. X and the nurses
4	MacMillan nurses □absolutely brilliant.
5	My experience in the Southern General □the nursing staff were excellent, patient and understanding. First class professionals.
6	Staff □because the explain things really well, most of them are sympathetic without being sugary
7	Consultants and nurses, even the pharmacy for making up my chemo. Everyone to do with oncology.
8	Medical profession □doctors and nurses. And family.
9	Both staff in here and the oncologist
10	Mostly medical staff and McMillan nurses
11	Doctors and everyone
12	The competence of nurses, surgeons specialists and so on
13	Prof George - I have been with him for 3 years and he did the operation
14	The surgeon and oncologist
15	Doctors and nurses. I don□t feel that family come into that equation, though I certainly have their support.
16	Doctors and professionals
17	Family and doctors

Determine patient response for item 32 □ don□t have cancer□ What do you think this question was designed to assess ? Tell me why you answered it the way that you did.

Comment Number	Comment/ Observations
1	Someone not accepting the fact that they have it
2	To see if they are in denial of cancer
3	Someone who is kidding themselves on, at the back of their mind, blocking it off
4	People who don□t want to accept it
5	Whether they are in denial
6	If someone is in denial
7	Maybe blanking it off, not accepting it and denying it.
8	I have no idea
9	People who refuse to accept the fact that they have
10	Whether you think that you have it or not

11	How you felt towards the cancer □trying to ignore it
12	This is designed to assess how someone puts a blanket down and will not accept
13	Pretending that you didn□t have it
14	Whether one has a positive attitude to fighting it or not
15	It depends on how you look at it - acceptance of whether you have it

What did you think that questionnaire was measuring ?

Comment Number	Comment/ Observations
1	I don□t know □I have accepted it, others might not
2	Probably to see how stable someone is during cancer treatment, whether they are coping. To see if it has affected them mentally in any way
3	How to handle other peoples problems, you□ve got to be positive, what is for you will not go by you
4	How you feel about cancer as an illness as well as having the illness □how you view it
5	Designed to measure the mental effects on emotions and whether you fully understand the implications of having a terminal illness.
6	My attitude about having cancer
7	Peoples attitudes to cancer and how they deal with it psychologically. How much their state of mind helps them in treatment and how well they are doing.
8	Trying to get patients outlook on their problems
9	Trying to establishing how reacting to cancer □the impact on life and how looking to the future □everyones conception of cancer will be different
10	Treatment or spread of the illness
11	How you feel about the whole thing of having cancer
12	Peoples mental attitude to the fact that they have or have had cancer, their reaction. It is designed to get a more positive response from people whom it destroys mentally
13	I think it is great. It gets the truth out of you and you can see what you are thinking about cancer, whether you worry about it
14	I think it was to get a reaction. It gets to the inside of your thoughts, you can□t hide anything. I think a lot of people will show emotion filling it in.
15	Whether the patient has a positive attitude to fighting cancer or not or whether they are resigned to accepting that this is the end for me
16	How people are reacting to being told, that they have it. How they are coping with it.
17	It was assessing your thoughts about cancer from start to finish. From when you got it to now and how you reacted. My outlook is positive.

Were there any items that were difficult to understand ? Which ones ?
How might you have rephrased this ?

Comment Number	Comment/ Observations
1	Not really
2	No it was all very straightforward
3	No
4	No
5	No
6	No
7	No
8	There were one or two. Did item 36 refer to being better off financially or health wise
9	No
10	That good things come out of cancer
11	No
12	Item 1. Dont□know
13	No, not to understand.
14	□No matter what happens□- this implies that things will get worse
15	Not really

Were there any items of the questionnaire which were annoying or upsetting ?
Which ones ?

Comment Number	Comment/ Observations
1	No
2	No
3	No
4	No
5	Item 12 makes the assumption that you believe in God
6	No
7	No
8	No
9	No
10	No
11	No
12	No
13	No
14	Could be for some people
15	Oh no, not at all
16	No
17	No

Were there questions which you found were irrelevant ?

Comment Number	Comment/ Observations
1	Not really
2	Not in particular to me
3	No
4	No
5	No
6	No
7	I was puzzled that intelligent people would ask some of the questions (e.g., good things)
8	No
9	That the cancer has spread
10	Yes (mostly those I did not agree with)
11	No
12	No
13	All the ones with nothings
14	No I wouldnt say so
15	No I don□ think so
16	No

Can you think of additional beliefs that are relevant for you but are not included in the questionnaire ?

Comment Number	Comment/ Observations
1	Don□ know
2	Possibly seeking alternative help and medicine □going hand in hand with conventional medicine.
3	Financial problems and family suffering more than the person with cancer
4	The support of the nursing staff, family and friends play an important part
5	It is all to do with emotions and these are very clinical questions. There is nothing to ask people about their emotions.
6	There is nothing specifically about the family there. Sometimes it is your family that you worry more about. They keep you going but you can□ bear the thought of them being upset.
7	Note that number 12 implies that believe in God
8	It has been pretty comprehensive really. One thing that has irritated me is the wait I had for treatment.
9	I thought that there might have been one about the shock of first being diagnosed
10	It is all bad - you could have some positive thoughts too
11	I don□ think so

Appendix 14
Core Cancer Meanings Measure for Main Validation Phase

CONFIDENTIAL

Your Thoughts about Cancer

Having cancer means different things to different people. This questionnaire contains a range of thoughts that people might have about their cancer. The purpose is for you to identify the thoughts that you hold about your cancer.

Please read each item carefully and rate how much you agree with each thought by circling a number to the right of the item. Each number in the right hand column refers to a different level of agreement with each thought:

0 indicates that you DO NOT AGREE with the thought
1 indicates that you AGREE SLIGHTLY with the thought
2 indicates that you AGREE MODERATELY with the thought
3 indicates that you AGREE VERY MUCH with the thought

ITEM NUMBER		DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
87	Cancer is a serious illness	0	1	2	3

↑ Read each thought and then decide how much you agree with it

↑ Circle a number to indicate how much you agree with each thought

Thank you for taking the time to complete this questionnaire.
If you have any questions then please contact Dr Craig White
Clinical Research Fellow in Psychosocial Oncology on 0141 211 3902.

ITEM NUMBER		DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
1	My cancer philosophy is □live for today□	0	1	2	3
2	Cancer rules my life	0	1	2	3
3	It is not fair that I developed cancer	0	1	2	3
4	I don□t plan for the future because of my cancer	0	1	2	3
5	Having cancer is a challenge to me	0	1	2	3
6	I cannot escape reminders that I have cancer	0	1	2	3
7	My world has fallen apart because of cancer	0	1	2	3
8	Cancer interferes with living my life	0	1	2	3
9	I think about my cancer all of the time	0	1	2	3
10	Cancer should not have happened to me	0	1	2	3
11	My thoughts about cancer are out of control	0	1	2	3
12	My faith will see me through having cancer	0	1	2	3
13	Cancer is not as bad as it is made out to be	0	1	2	3
14	Cancer has changed every aspect of my life	0	1	2	3
15	I appreciate life more because of cancer	0	1	2	3
16	Everything about cancer is bad news	0	1	2	3
17	Other people pity me because I have cancer	0	1	2	3
18	My life has been shattered because of cancer	0	1	2	3
19	I am a completely different person because of my cancer	0	1	2	3
20	I accept that I have had cancer	0	1	2	3

ITEM NUMBER		DO NOT AGREE	AGREE SLIGHTLY	AGREE MODERATELY	AGREE VERY MUCH
21	I think that I will be cured of my cancer	0	1	2	3
22	I have control over my cancer experiences	0	1	2	3
23	Cancer is a death sentence	0	1	2	3
24	Some good things have come from my having had cancer	0	1	2	3
25	I am more fortunate than most people who have cancer	0	1	2	3
26	Other people do not understand what it is like to have cancer	0	1	2	3
27	I keep thinking that my cancer might come back or might spread	0	1	2	3
28	Cancer has made me really focus on what matters in my life	0	1	2	3
29	I wonder if my cancer has spread	0	1	2	3
30	I must have done something wrong in my life to have developed cancer	0	1	2	3
31	Other peoples reactions to my cancer make me pessimistic	0	1	2	3
32	There are worse things that could have happened to me than having cancer	0	1	2	3
33	I have no future because of cancer	0	1	2	3
34	Luck will determine what will happen to my cancer	0	1	2	3
35	Others I know with cancer have inspired me	0	1	2	3
36	I have some control over the course of my cancer	0	1	2	3
37	I don□ understand what is happening with my cancer care	0	1	2	3
38	Other people□s reactions to my cancer give me hope	0	1	2	3
39	I have lost control of my life because of cancer	0	1	2	3
40	My life has more meaning because of cancer	0	1	2	3

My cancer philosophy is "live for today"

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	10	7.1	7.2	7.2
	agree slightly	24	17.0	17.4	24.6
	agree moderatlely	31	22.0	22.5	47.1
	agree very much	73	51.8	52.9	100.0
	Total	138	97.9	100.0	
Missing	9	3	2.1		
Total		141	100.0		

Cancer rules my life

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	95	67.4	68.8	68.8
	agree slightly	18	12.8	13.0	81.9
	agree moderatlely	11	7.8	8.0	89.9
	agree very much	14	9.9	10.1	100.0
	Total	138	97.9	100.0	
Missing	9	3	2.1		
Total		141	100.0		

It is not fair that I developed cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	72	51.1	52.2	52.2
	agree slightly	32	22.7	23.2	75.4
	agree moderatlely	15	10.6	10.9	86.2
	agree very much	19	13.5	13.8	100.0
	Total	138	97.9	100.0	
Missing	9	2	1.4		
	System	1	.7		
	Total	3	2.1		
Total		141	100.0		

I don't plan for the future because of my cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	92	65.2	65.2	65.2
	agree slightly	22	15.6	15.6	80.9
	agree moderatlely	12	8.5	8.5	89.4
	agree very much	15	10.6	10.6	100.0
	Total	141	100.0	100.0	

Having cancer is a challenge to me

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	29	20.6	21.0	21.0
	agree slightly	23	16.3	16.7	37.7
	agree moderatlely	32	22.7	23.2	60.9
	agree very much	54	38.3	39.1	100.0
	Total	138	97.9	100.0	
Missing	9	3	2.1		
Total		141	100.0		

I cannot escape reminders that I have cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	29	20.6	21.2	21.2
	agree slightly	44	31.2	32.1	53.3
	agree moderatlely	31	22.0	22.6	75.9
	agree very much	33	23.4	24.1	100.0
	Total	137	97.2	100.0	
Missing	9	4	2.8		
Total		141	100.0		

My world has fallen apart because of cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	92	65.2	65.7	65.7
	agree slightly	24	17.0	17.1	82.9
	agree moderatlely	15	10.6	10.7	93.6
	agree very much	9	6.4	6.4	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

Cancer interferes with living my life

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	54	38.3	38.8	38.8
	agree slightly	39	27.7	28.1	66.9
	agree moderatlely	27	19.1	19.4	86.3
	agree very much	19	13.5	13.7	100.0
	Total	139	98.6	100.0	
Missing	9	1	.7		
	System	1	.7		
	Total	2	1.4		
Total		141	100.0		

I think about my cancer all the time

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	82	58.2	59.0	59.0
	agree slightly	32	22.7	23.0	82.0
	agree moderatlely	18	12.8	12.9	95.0
	agree very much	7	5.0	5.0	100.0
	Total	139	98.6	100.0	
Missing	9	2	1.4		
Total		141	100.0		

Cancer should not have happened to me

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	78	55.3	55.7	55.7
	agree slightly	23	16.3	16.4	72.1
	agree moderatlely	15	10.6	10.7	82.9
	agree very much	24	17.0	17.1	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

My thoughts about cancer are out of control

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	119	84.4	85.6	85.6
	agree slightly	12	8.5	8.6	94.2
	agree moderatlely	6	4.3	4.3	98.6
	agree very much	2	1.4	1.4	100.0
	Total	139	98.6	100.0	
Missing	9	2	1.4		
Total		141	100.0		

My faith will see me through having cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	24	17.0	17.1	17.1
	agree slightly	28	19.9	20.0	37.1
	agree moderatlely	31	22.0	22.1	59.3
	agree very much	57	40.4	40.7	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

Cancer is not as bad as it is made out to be

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	45	31.9	32.6	32.6
	agree slightly	29	20.6	21.0	53.6
	agree moderatlely	40	28.4	29.0	82.6
	agree very much	24	17.0	17.4	100.0
	Total	138	97.9	100.0	
Missing	9	3	2.1		
Total		141	100.0		

Cancer has changed every aspect of my life

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	70	49.6	49.6	49.6
	agree slightly	31	22.0	22.0	71.6
	agree moderatlely	20	14.2	14.2	85.8
	agree very much	20	14.2	14.2	100.0
	Total	141	100.0	100.0	

I appreciate life more because of cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	19	13.5	13.5	13.5
	agree slightly	26	18.4	18.4	31.9
	agree moderatlely	20	14.2	14.2	46.1
	agree very much	76	53.9	53.9	100.0
	Total	141	100.0	100.0	

Everything about cancer is bad news

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	78	55.3	55.7	55.7
	agree slightly	19	13.5	13.6	69.3
	agree moderatlely	22	15.6	15.7	85.0
	agree very much	21	14.9	15.0	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

Other people pity me because I have cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	54	38.3	38.6	38.6
	agree slightly	44	31.2	31.4	70.0
	agree moderatlely	24	17.0	17.1	87.1
	agree very much	18	12.8	12.9	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

My life has been shattered because of cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	91	64.5	64.5	64.5
	agree slightly	21	14.9	14.9	79.4
	agree moderatlely	18	12.8	12.8	92.2
	agree very much	11	7.8	7.8	100.0
	Total	141	100.0	100.0	

I am a completely different person because of my cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	78	55.3	56.1	56.1
	agree slightly	36	25.5	25.9	82.0
	agree moderatlely	15	10.6	10.8	92.8
	agree very much	10	7.1	7.2	100.0
	Total	139	98.6	100.0	
Missing	9	2	1.4		
Total		141	100.0		

I accept that I have had cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	3	2.1	2.2	2.2
	agree slightly	4	2.8	2.9	5.1
	agree moderatlely	11	7.8	8.0	13.0
	agree very much	120	85.1	87.0	100.0
	Total	138	97.9	100.0	
Missing	9	2	1.4		
	System	1	.7		
	Total	3	2.1		
Total		141	100.0		

I think that I will be cured of my cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	14	9.9	10.1	10.1
	agree slightly	17	12.1	12.2	22.3
	agree moderatlely	37	26.2	26.6	48.9
	agree very much	71	50.4	51.1	100.0
	Total	139	98.6	100.0	
Missing	9	2	1.4		
Total		141	100.0		

I have control over my cancer experiences

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	12	8.5	8.9	8.9
	agree slightly	23	16.3	17.0	25.9
	agree moderatlely	48	34.0	35.6	61.5
	agree very much	52	36.9	38.5	100.0
	Total	135	95.7	100.0	
Missing	9	6	4.3		
Total		141	100.0		

Cancer is a death sentence

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	102	72.3	72.9	72.9
	agree slightly	16	11.3	11.4	84.3
	agree moderatlely	10	7.1	7.1	91.4
	agree very much	12	8.5	8.6	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

some good things have come from having had cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	38	27.0	27.3	27.3
	agree slightly	42	29.8	30.2	57.6
	agree moderatlely	32	22.7	23.0	80.6
	agree very much	27	19.1	19.4	100.0
	Total	139	98.6	100.0	
Missing	9	2	1.4		
Total		141	100.0		

I am more fortunate than most people who have cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	19	13.5	14.1	14.1
	agree slightly	16	11.3	11.9	25.9
	agree moderatlely	36	25.5	26.7	52.6
	agree very much	64	45.4	47.4	100.0
	Total	135	95.7	100.0	
Missing	9	6	4.3		
Total		141	100.0		

Other people do not understand what it is like to have cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	21	14.9	15.0	15.0
	agree slightly	41	29.1	29.3	44.3
	agree moderatlely	38	27.0	27.1	71.4
	agree very much	40	28.4	28.6	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

I keep thinking that my cancer might spread or might come back

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	28	19.9	20.0	20.0
	agree slightly	47	33.3	33.6	53.6
	agree moderatlely	31	22.0	22.1	75.7
	agree very much	34	24.1	24.3	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

Cancer has really made me focus on what matters in life

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	15	10.6	10.6	10.6
	agree slightly	18	12.8	12.8	23.4
	agree moderatlely	26	18.4	18.4	41.8
	agree very much	82	58.2	58.2	100.0
	Total	141	100.0	100.0	

I wonder if my cancer has spread

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	37	26.2	26.8	26.8
	agree slightly	47	33.3	34.1	60.9
	agree moderatlely	27	19.1	19.6	80.4
	agree very much	27	19.1	19.6	100.0
	Total	138	97.9	100.0	
Missing	9	3	2.1		
Total		141	100.0		

I must have done something wrong in my life to have developed cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	119	84.4	85.0	85.0
	agree slightly	11	7.8	7.9	92.9
	agree moderatlely	5	3.5	3.6	96.4
	agree very much	5	3.5	3.6	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

Other peoples reactions to my cancer make me pessimistic

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	90	63.8	65.7	65.7
	agree slightly	29	20.6	21.2	86.9
	agree moderatlely	12	8.5	8.8	95.6
	agree very much	6	4.3	4.4	100.0
	Total	137	97.2	100.0	
Missing	9	4	2.8		
Total		141	100.0		

There are worse things that could have happened to me than having cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	18	12.8	12.9	12.9
	agree slightly	21	14.9	15.0	27.9
	agree moderatlely	26	18.4	18.6	46.4
	agree very much	75	53.2	53.6	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

I have no future because of cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	116	82.3	82.9	82.9
	agree slightly	13	9.2	9.3	92.1
	agree moderatlely	7	5.0	5.0	97.1
	agree very much	4	2.8	2.9	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

Luck will determine what happens to my cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	79	56.0	57.2	57.2
	agree slightly	29	20.6	21.0	78.3
	agree moderatlely	13	9.2	9.4	87.7
	agree very much	17	12.1	12.3	100.0
	Total	138	97.9	100.0	
Missing	9	3	2.1		
Total		141	100.0		

Others I know with cancer have inspired me

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	13	9.2	9.3	9.3
	agree slightly	20	14.2	14.3	23.6
	agree moderatlely	33	23.4	23.6	47.1
	agree very much	74	52.5	52.9	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

I have some control over the course of my cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	38	27.0	27.3	27.3
	agree slightly	36	25.5	25.9	53.2
	agree moderatlely	35	24.8	25.2	78.4
	agree very much	30	21.3	21.6	100.0
	Total	139	98.6	100.0	
Missing	9	2	1.4		
Total		141	100.0		

I don't understand what is happening with my cancer care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	107	75.9	76.4	76.4
	agree slightly	13	9.2	9.3	85.7
	agree moderatlely	12	8.5	8.6	94.3
	agree very much	8	5.7	5.7	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

Other people's reaction to my cancer gives me hope

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	13	9.2	9.4	9.4
	agree slightly	23	16.3	16.7	26.1
	agree moderatlely	33	23.4	23.9	50.0
	agree very much	69	48.9	50.0	100.0
	Total	138	97.9	100.0	
Missing	9	3	2.1		
Total		141	100.0		

I have lost control of my life because of cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	117	83.0	83.6	83.6
	agree slightly	9	6.4	6.4	90.0
	agree moderatlely	10	7.1	7.1	97.1
	agree very much	4	2.8	2.9	100.0
	Total	140	99.3	100.0	
Missing	9	1	.7		
Total		141	100.0		

My life has more meaning because of cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Do not agree	37	26.2	26.6	26.6
	agree slightly	21	14.9	15.1	41.7
	agree moderatlely	23	16.3	16.5	58.3
	agree very much	58	41.1	41.7	100.0
	Total	139	98.6	100.0	
Missing	9	1	.7		
	System	1	.7		
	Total	2	1.4		
Total		141	100.0		

Appendix 16

Percentage of Responses Endorsed by Tumour Site and Disease Status for Each CCMM Item

Item: 1 Cancer rules my life (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic (n = 23)
Do Not Agree	74	62	62	76	76	56
Agree Slightly	12	9	14	7	5	26
Agree Moderately	3	17	5	4	8	9
Agree Very Much	10	9	14	13	11	9

Item: 2 It is not fair that I developed cancer (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 19)	Localised	Locoregional	Metastatic
Do Not Agree	57	50	38	58	54	48
Agree Slightly	24	24	19	21	24	13
Agree Moderately	7	9	24	15	8	4
Agree Very Much	10	17	9	6	14	35

Item: 3 I don't plan for the future because of my cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	76	62	38	74	69	52
Agree Slightly	13	21	19	15	15	17
Agree Moderately	3	5	24	6	5	13
Agree Very Much	7	12	9	6	10	17

Item: 4 Cancer is a challenge (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	25	7	24	21	21	14
Agree Slightly	16	17	19	23	16	9
Agree Moderately	22	21	29	23	21	27
Agree Very Much	35	52	29	34	44	50

Item: 5 I cannot escape reminders that I have cancer (Total Patients)	Breast (n = 66)	Colorectal (n = 41)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	21	19	19	23	18	19
Agree Slightly	28	31	33	39	26	19
Agree Moderately	26	19	24	15	36	19
Agree Very Much	22	27	19	23	21	43

Item: 6 My world has fallen apart because of my cancer (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	69	60	62	70	71	56
Agree Slightly	19	17	10	17	8	22
Agree Moderately	9	17	10	6	21	9
Agree Very Much	2	7	19	7	0	13

Item: 7 Cancer interferes with living my life (Total Patients)	Breast (n = 66)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	47	33	33	43	44	37
Agree Slightly	28	31	14	28	23	37
Agree Moderately	13	24	19	9	23	14
Agree Very Much	8	12	33	19	10	14

Item: 8 I think about my cancer all of the time (Total Patients)	Breast (n = 68)	Colorectal (n = 41)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	62	52	57	71	55	48
Agree Slightly	22	21	19	11	24	22
Agree Moderately	12	14	19	11	16	26
Agree Very Much	4	9	0	6	5	4

Item: 9 Cancer should not have happened to me (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	65	48	48	66	51	44
Agree Slightly	15	14	19	13	18	17
Agree Moderately	10	9	14	11	16	0
Agree Very Much	10	29	14	9	16	39

Item: 10 My thoughts about cancer are out of control (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	88	79	81	91	84	78
Agree Slightly	4	14	14	7	5	17
Agree Moderately	4	5	0	0	10	4
Agree Very Much	1	2	0	2	0	0

Item: 11 My faith in God will see me through my cancer (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	22	7	14	17	18	9
Agree Slightly	24	14	19	26	21	4
Agree Moderately	16	29	29	21	21	27
Agree Very Much	37	50	38	37	41	59

Item: 12 Cancer is not as bad as it is made out to be (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 19)	Localised	Locoregional	Metastatic
Do Not Agree	24	38	43	31	29	48
Agree Slightly	22	24	9	15	26	4
Agree Moderately	31	24	33	36	26	30
Agree Very Much	22	14	5	19	18	17

Item: 13 Cancer has changed every aspect of my life (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	53	60	29	61	49	39
Agree Slightly	24	12	43	21	23	17
Agree Moderately	15	14	14	4	20	30
Agree Very Much	9	14	14	15	7	13

Item: 14 I appreciate life more because of cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	18	7	9	15	18	13
Agree Slightly	15	24	19	26	15	9
Agree Moderately	15	12	24	21	10	0
Agree Very Much	53	57	48	39	56	78

Item: 15 Everything about cancer is bad news (Total Patients)	Breast (n = 68)	Colorectal (n = 41)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	68	48	33	57	61	36
Agree Slightly	12	17	19	11	13	23
Agree Moderately	15	14	19	17	15	14
Agree Very Much	6	19	29	15	10	27

Item: 16 Other people pity me because I have cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	31	50	38	36	38	44
Agree Slightly	40	21	24	40	31	22
Agree Moderately	16	17	19	19	13	17
Agree Very Much	13	12	14	6	18	17

Item: 17 My life has been shattered because of cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	72	62	57	74	72	48
Agree Slightly	16	12	9	11	8	26
Agree Moderately	8	17	14	4	21	13
Agree Very Much	3	9	19	11	0	13

Item: 18 I am a completely different person because of my cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 41)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	57	55	48	58	62	52
Agree Slightly	26	17	38	30	21	17
Agree Moderately	10	14	9	7	13	13
Agree Very Much	6	12	0	4	5	17

Item: 19 I accept that I have cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 40)	Lung (n = 22)	Localised	Locoregional	Metastatic
Do Not Agree	1	5	0	0	0	0
Agree Slightly	3	0	0	7	0	0
Agree Moderately	10	2	4	6	7	4
Agree Very Much	85	88	91	82	92	95

Item: 20 I know that I will be cured of my cancer (Total Patients)	Breast (n = 66)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	3	7	24	11	16	17
Agree Slightly	7	17	14	7	0	17
Agree Moderately	30	24	29	25	24	39
Agree Very Much	59	52	33	57	61	26

Item: 21 I have no control over any aspects of my cancer experiences (Total Patients)	Breast (n = 64)	Colorectal (n = 42)	Lung (n = 19)	Localised	Locoregional	Metastatic
Do Not Agree	8	12	10	6	14	17
Agree Slightly	14	19	21	12	19	18
Agree Moderately	31	40	37	39	24	45
Agree Very Much	47	29	32	43	43	23

Item: 22 Cancer is a death sentence (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	85	74	50	79	82	48
Agree Slightly	4	7	35	11	3	22
Agree Moderately	7	7	5	2	13	13
Agree Very Much	3	12	10	7	3	17

Item: 23 There are some good things about having cancer (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung	Localised	Locoregional	Metastatic
Do Not Agree	21	21	55	31	21	30
Agree Slightly	31	36	15	42	23	22
Agree Moderately	27	24	15	14	33	26
Agree Very Much	21	19	15	14	23	22

Item: 24 (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 19)	Localised	Locoregional	Metastatic
Do Not Agree	7	21	21	16	11	13
Agree Slightly	15	36	16	8	16	13
Agree Moderately	24	24	26	24	22	35
Agree Very Much	54	19	37	53	51	39

Item: 25 Other people do not understand what it is like to have cancer (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 21)	Localised	Locoregional	Metastatic
Do Not Agree	15	19	9	20	11	4
Agree Slightly	30	29	29	35	18	35
Agree Moderately	31	26	14	20	47	22
Agree Very Much	24	26	48	24	24	39

Item: 26 I wonder if my cancer has spread (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	25	17	9	25	21	17
Agree Slightly	35	26	38	40	28	9
Agree Moderately	26	21	19	25	28	26
Agree Very Much	13	36	29	11	23	48

Item: 27 Cancer makes you focus on what really matters (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 23)	Localised	Locoregional	Metastatic
Do Not Agree	13	7	9	9	18	9
Agree Slightly	15	5	4	20	10	4
Agree Moderately	19	21	26	19	13	26
Agree Very Much	53	67	61	52	59	61

Item: 28 Spread ??? (Total Patients)	Breast (n = 68)	Colorectal (n = 41)	Lung (n = 22)	Localised	Locoregional	Metastatic
Do Not Agree	27	20	18	34	29	19
Agree Slightly	40	39	23	40	32	23
Agree Moderately	22	7	17	21	18	14
Agree Very Much	12	34	45	6	21	45

Item: 29 I must have done something wrong in life to have developed cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	87	79	90	92	82	74
Agree Slightly	9	9	5	4	10	13
Agree Moderately	4	2	0	2	5	4
Agree Very Much		9	5	2	3	9

Item: 30 Other people's reactions to my cancer make me pessimistic (Total Patients)	Breast (n = 65)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	68	59	70	66	69	61
Agree Slightly	18	24	25	27	11	26
Agree Moderately	11	9	5	6	17	13
Agree Very Much	3	7	0	2	3	0

Item: 31 There are worse things that could have happened to me than having cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	13	9	15	17	15	9
Agree Slightly	16	17	10	8	28	0
Agree Moderately	17	17	25	21	18	22
Agree Very Much	53	57	50	55	39	70

Item: 32 I have no future because of cancer (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	93	79	80	91	87	74
Agree Slightly	3	14	5	2	8	18
Agree Moderately	4	7	5	6	3	9
Agree Very Much	0	0	10	2	3	0

Item: 33 Luck will determine what will happen to my cancer (Total Patients)	Breast (n = 65)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	93	52	48	61	60	44
Agree Slightly	3	19	14	27	11	26
Agree Moderately	4	14	14	4	16	9
Agree Very Much		14	24	10	14	22

Item: 34 Others I know with cancer have inspired me (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	4	9	20	9	10	9
Agree Slightly	13	19	10	15	10	22
Agree Moderately	28	21	20	30	21	17
Agree Very Much	54	50	50	45	59	52

Item: 35 (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	21	29	35	19	33	30
Agree Slightly	33	19	25	35	26	17
Agree Moderately	25	26	25	23	28	30
Agree Very Much	20	26	15	23	13	22

Item: 36 There is so much about my cancer experience that I don't understand (Total Patients)	Breast (n = 68)	Colorectal (n = 42)	Lung (n = 20)	Localised	Locoregional	Metastatic
Do Not Agree	81	74	75	81	69	74
Agree Slightly	7	9	10	7	10	13
Agree Moderately	7	9	10	9	8	9
Agree Very Much	4	7	5	2	13	4

Item: 37 Other people's reaction to my cancer give me hope (Total Patients)	Breast (n = 67)	Colorectal (n = 42)	Lung (n = 19)	Localised	Locoregional	Metastatic
Do Not Agree	7	7	16	13	3	13
Agree Slightly	16	17	21	17	11	22
Agree Moderately	22	26	26	27	26	13
Agree Very Much	54	50	37	42	61	52

Item: 38 I have lost control of my life because of cancer (Total Patients)	Breast	Colorectal	Lung	Localised	Locoregional	Metastatic
Do Not Agree	85	83	85	91	90	78
Agree Slightly	6	7	5	0	3	9
Agree Moderately	3	10	10	6	3	13
Agree Very Much	6	0	0	4	5	0

Item: 39 (Total Patients)	Breast	Colorectal	Lung	Localised (n = 54)	Locoregional (n = 39)	Metastatic (n = 23)
Do Not Agree	29	21	24	27	39	13
Agree Slightly	20	17	5	17	15	9
Agree Moderately	17	17	19	19	8	30
Agree Very Much	35	45	52	36	39	48

Item: 40 My cancer philosophy is live for today (Total Patients)	Breast	Colorectal	Lung	Localised	Locoregional	Metastatic
Do Not Agree	9	5	5	9	5	9
Agree Slightly	17	22	20	14	26	14
Agree Moderately	24	24	10	26	23	14
Agree Very Much	51	49	65	48	46	63

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Our RefAC-290/Jul00I/MG Your Ref. DDI: 01292 885859

24 August 2000

Dr C A White
CRC Fellow in Psychosocial Oncology
University of Glasgow
Dept of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
GLASGOW
G12 0XH

Dr Craig A. White
CRC Fellow in Psychosocial Oncology
Psychological Medicine
University of Glasgow

Date Received:	28 AUG 2000
Action:	
Copy to:	CAE, JSW, DR, GE
File:	

Dear Dr White

Validation of the core cancer meanings measure

Further to your letter of 9 August 2000 clarifying the points raised in my letter of 17 July 2000, I am pleased to inform you that the study may now proceed.

The terms of approval state that:

- The written consent of patients participating in the study must be obtained. The patient information sheet and consent form and the manner in which you intend to seek consent are acceptable.

- Regular reports on the progress of the study require to be submitted and your first report should be submitted to myself in six months time and subsequently at yearly intervals until the work is completed.

- As indicated in the guidance notes to researchers, a copy of which you were supplied with, you will require to seek the permission of the responsible NHS body within the Board's area prior to proceeding with this project. In this respect you should contact Mr Gerry Watson, Medical Director of the Ayrshire and Arran Acute Hospitals NHS Trust, to confirm that management have no objections to the study going ahead.

The Ayrshire and Arran Local Research Ethics Committee operates in accordance with current guidelines set down by the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use. *(E6 Good Clinical Practice* : Consolidated Guidelines (Step 4). ICH 1996.)

I enclose a copy of the Constitution of Ayrshire and Arran Local Research Ethics Committee, together with a list of the membership of the Committee.

On behalf of the Committee may I take this opportunity of wishing you every success with the research project.

Yours sincerely

Dr Adrian Carr
Secretary – Local Research Ethics Committee

Encs

Cc: Mr Gerry Watson, Medical Director, Ayrshire and Arran Acute Hospitals NHS Trust, Crosshouse Hospital, By Kilmarnock, KA2 0BE.

cancer research campaign

CRC Fellow in Psychosocial Oncology
Dr Craig A White, ClinPsyD AFBPsS C Psychol

UNIVERSITY *of* GLASGOW

19/06/00

Understanding Thoughts About Cancer

You are being invited to participate in a research study funded by the Cancer Research Campaign in association with the University of Glasgow. Before you decide on whether you would wish to take part it is important that you understand why this research is being done and will taking part will involve. Please read the following information carefully and discuss it with friends, relatives and your GP if you wish. If you would like any more information or you have any questions then I will be happy to answer these. Take time to decide whether or not you wish to take part. I can be contacted by telephoning 0141 211 0694 or 01292 285607.

The aim of this research is to understand more about they way in which cancer and cancer treatments affect they way people think. Previous research has shown that cancer can be associated with feeling anxious or depressed and that these feelings are associated with particular thinking patterns. You have been invited to take part in this study because you have been attending the cancer unit at Ayr or Crosshouse Hospitals. You do not have to take part and if you decide not to then your care will not be affected in any way.

If you do decide to take part then you will be invited to fill in some questionnaires concerning your experiences relating to cancer. I have attached a FREEPOST (no stamp required) envelope for you to return the questionnaires to me. If your responses to these questionnaires indicate that you have been having problems with how you are thinking or feeling in relation to cancer, then I will contact you to discuss the ways in which you may be able to get some help with this.

Taking part in this study may not be of direct benefit to you but could help in the development of psychological assessment and treatment methods for future patients. Your involvement with the research study is complete when you hand over or return the fully completed questionnaires. Each questionnaire is allocated a number and will be stored securely under lock and key at the Department of Psychological Medicine at the University of Glasgow.

I am grateful to you for taking the time to consider this invitation

Yours sincerely

Dr. Craig A. White

DEPARTMENT OF PSYCHOLOGICAL MEDICINE
Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH
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Head of Department: Professor C A Espie *Head of Department:* Professor C A Esp

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GLASGOW

CONSENT FORM

Title of Project: Understanding Thoughts About Cancer

Name of Researcher: Dr. Craig A. White

Please initial box

1. I confirm that I have read and understand the information sheet dated 19th June 2000 for the above study and have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected	
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from Department of Psychological Medicine, University of Glasgow or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records in connection with this study only.	
4. I agree to take part in the above study	

Name of Patient	Date	Signature
Name of Person taking consent (if different from Researcher)	Date	Signature
Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes